- INVISIBLE -

THE NOTION OF DISABILITY IN THE CONTEXT OF HIV/AIDS IN KWAZULU-NATAL, SOUTH AFRICA

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„For Tembelihle“

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DECLARATION

English:

In accordance with the regulations of the Humboldt University Berlin, I, Jill Hanass-Hancock, declare that this PHD thesis entitled: ´-Invisible- The notion of disability in the context of HIV/AIDS in KwaZulu-Natal, South Africa´ is my original research. It has not been previously submitted for any degree, and is not being concurrently presented in candidature at any other University. All sources of literature have been duly acknowledged.

German:

Hiermit erkläre ich, dass meine Dissertation ´-Invisible- The notion of disability in the context of HIV/AIDS in KwaZulu-Natal, South Africa´ meine persönliche Arbeit darstellt und in Übereinstimmung mit den Regulationen zur Erlangung des akademischen Grades ´Dr. phil.´ geschrieben wurden. Diese Dissertation wird erstmalig eingereicht. Alle von mir benutzten Quellen sind gekennzeichnet. Außerdem wurde die Dissertation in Englisch vorgelegt, damit auch die Menschen, die mich während meiner Forschungen unterstützt haben, von meiner Arbeit Nutzen ziehen können.

Date 31.01.2008 Jill Hanass-Hancock

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ABSTRACT

This thesis is an attempt to understand the cultural roots of non-medical representations of disability and HIV/AIDS in KwaZulu-Natal. It argues that the way in which people are prone to think about and respond to disability and HIV/AIDS, exposes people with disability to a particularly high risk of infection while simultaneously decreasing access to treatment and care. While unfolding hidden meanings and notions about disability and HIV/AIDS, this thesis analyses both phenomena on a macrocultural, microcultural and individual level.

From a macrocultural perspective it is positioned in a historical context that tries to picture KwaZulu-Natal in its present stage and shows how the phenomena of disability and HIV/AIDS are contextualised in society at large. It reflects on the need for the modern state of South Africa to find an African identity without losing the connection to the modern era in which the HIV/AIDS pandemic has evolved. In this context it tries to show how the phenomenon of disability is just one of many issues that the new South Africa faces and that at the present moment, a tremendous need to overcome access barriers still persists.

From a microcultural perspective notions about womanhood as well as disability and HIV/AIDS affect the way people think about and interact with each other. The effects of gender inequality have been clearly analysed by many previous writers and scientists agree that in KwaZulu-Natal women are still marginalized. While sexes are a matter of fact the identification of disability depends on threshold. This threshold for perceiving a condition as abnormal precedes the interpretation process of abnormalities, and with this disability. Once a condition is recognized as abnormal the personal interpretation or Subjective Theory about the condition determines attributions to it. These Subjective Theories are based on the Social Representations of abnormalities and with this also about disability and HIV/AIDS. These Subjective Theories and Social Representations will be unwrapped in this thesis and juxtaposed with each other. It will be shown that diseases and disabilities can be interpreted as being caused naturally or spiritually. In addition to this the concepts of protection (e.g. ancestors) and pollution (e.g. death) will be explained. The thesis will argue that some of these notions about disability positively affect the interaction with disabled

people, while others have a negative effect. The African way of ritual ancestor worship or ´cleansing´ can help to raise the acceptance of a disabled family member. This however depends on the interpretation of the disability. Another interpretation of the condition can have the opposite effect and increase exclusion.

In the context of HIV/AIDS the conceptualisation of disability raises a number of misconceptions that expose people with disability to HIV. As this thesis looks into disability in the context of HIV/AIDS it also inquires into the historical and cultural setting of the epidemic as well as the notion about the disease. It shows that even after 15 years of AIDS education, the disease is still surrounded by myths and contradicting messages are still being sent out from the various sources. It will be shown that the “nationalist/ameliorative” paradigm has received a greater emphasis from the current government in an attempt to find an “African solution” to the pandemic. This has led to a one-sided approach, which focuses on poverty, palliative care, traditional medicine and appropriate nutrition. It will be argued, that while the conceptualisation of an African identity is historically a very important development, in the context of HIV/AIDS it seems to have been something of a “Trojan horse”. This has prevented African leaders from questioning the so-called “African traditions” that have proven to be rather detrimental in the ´fight´ against AIDS.

In this context misconceptions about HIV prevention, causes and treatments, the tabooing of sexuality and a lack of emancipation have, besides other HIV determinants, exposed women, in particular, to abusive situations and HIV. In addition to this, common notions about disability have further complicated the matter. It will be further demonstrated that these notions result in people with disability being very vulnerable to sexual exploitation. Women and girls with disabilities are especially used for sexual purification rituals, are sexually exploited and have less access to prevention and treatment.

In relation to this situation, this thesis discusses three coping strategies on a more individual level. Case studies will show that only the empowered and enlightened individual can develop into a person who can negotiate safer sexual practices.

The thesis concludes with key messages on three social levels emerging from the empirical research as well as from historical and policy analysis. Through this, it attempts to provide some guidance for transformation.

ABBREVIATIONS

ACT	- AIDS Communication Team
AIDS	- Acquired Immune Deficiency Disorder
AFUB	- African Union for the Blind
ANC	- African National Congress
ARV	- Antiretroviral
ART	- Antiretroviral Treatment
ASSA	- Actuarial Society of South Africa
CBR	- Community Based Rehabilitation
CD4	- Indicator for the functioning of the Immune system. CD4 cells are counted in people that suffer from AIDS. A measurement of under 200 CD4 cells indicates the need for ARV treatment.
CHC	- Community Health Centres
CHW	- Community Health Worker
CP	- Cerebral Palsy
DHS	- District Health System
DICAG	- Disabled Children Action Group
DPSA	- Disabled People South Africa
DSM	- Diagnostic and Statistical Manual on Mental Disorders
GNI	- Gross National Income per capita
GPS	- Global Positioning System
HAART	- Highly Active Antiretroviral Therapy
HBM	- Health Belief Models
HCBC	- Home Community Based Care
HCBP	- Home Community Based Programmes
HDI	- Human Development Index
HEARD	- Health Economy and HIV/AIDS Research Division
HIV	- Human Immunodeficiency Virus
HR	- Human Resources
ICIDH	- International Classification of Impairment, Disability and Handicap
ICF	- International Classification of Function, Disability and Health
IKS	- Indigenous Knowledge System

KAP	- Knowledge, Attitude and Practice (type of assessment)
KZN	- KwaZulu-Natal
MRC	- Medical Research Council of South Africa
MTCTP	- Mother To Child Transmission Protection
NGO	- None Government Organisation
PHC	- Primary Health Care
PAR	- Participatory Action Research
RAP	- Rapid Assessment Procedure
SPHC	- Selective Primary Health Care
STD	- Sexually Transmitted Disease
TAC	- Treatment Action Campaign
TB	- Tuberculosis
TBA	- Traditional Birth Attendance
THP	- Traditional Health Practitioner
VTC	- Volunteer Testing and Counselling
WHO	- World Health Organisation

PART I

INTRODUCTION TO THIS STUDY

1 INTRODUCTION

1.1 FOREWORD

This thesis is not only the work of a three-year PhD[1] study, but it is also the culmination of a chapter in my personal development that started almost 14 years ago. In 1995 I had my first intense encounter with Zulu speaking people when I worked as a volunteer in a mother and child project in Marianhill, outside Durban. I have always been interested in the cultural and spiritual aspects of African society, but following my experiences I developed a specific interest in KwaZulu-Natal. Having spent most of my adult life working with children with special needs in Germany, I noticed that the understanding of disability in an African context differs from the interpretation of the phenomenon in Europe. During this time HIV/AIDS[2] has become a serious epidemic in South Africa and especially here in KwaZulu-Natal. AIDS researchers moved quickly to study the disabling effects of HIV/AIDS on previously healthy people, however it has taken a long time for research to acknowledge that people with disability are also at risk to HIV infection. It soon became apparent that the phenomenon of disability is largely mystified in South Africa, which has left space for a tremendous amount of interpretation. In the context of HIV/AIDS for instance, people used to believe that people with disability are not sexually active and therefore don't need sexual education. Furthermore HIV/AIDS awareness programmes were often ineffective at a local level, as they were designed by outside experts who were ignorant of local realities and who were seldom aware of the particular problems of disabilities (Dube 2004). As a result little effort was taken to adapt awareness programmes for the needs of disabled people. This ignorance denied people with disabilities the necessary education and therefore placed them at risk of exposure to infections. In recent years, however, attention has been drawn to the fact that HIV/AIDS awareness programmes also need to incorporate disabled people (Groce 2004).

The lack of sexual education and exposure to sexually related topics was not however the only problem. It almost appeared as if people with disabilities were

[1] PhD - Doctor in Philosophy
[2] HIV/AIDS - Human Immunodeficiency Virus / Acquired Immune Deficiency Syndrome

especially vulnerable to HIV/AIDS, but nobody really knew to what extent and why. The cultural interpretation of disability seemed somehow to play a role. I therefore started to become interested in the hidden meanings and the conceptualisation of disability. Encouraged by both friends and family, I started to research the field and discovered that there was a need for further knowledge and that it would be a good base for a dissertation.

While I found an abundance of literature on HIV/AIDS there was no work available that explored the connection between concepts of disability and HIV infection in KwaZulu-Natal. In fact there was hardly any literature on the cultural meaning of disability in KwaZulu-Natal at all. Motivated to unwrap the link between the two I started to work on this thesis.

1.2 PURPOSE OF THIS STUDY

This thesis is essentially an attempt to understand the cultural roots of non-medical representations of disability in KwaZulu-Natal. It is argued that these representations affect the way in which people are prone to think about and respond to disabled people and which ultimately affects the degree to which a person is exposed to HIV-infection risks.

Scientists, who turn their professional attention and research activities to disability, start with the understanding that disability is more than a simple medical problem. It is also a cultural construction (Dederich 2007; Üstün et al. 2001). Disability from an anthropological perspective is heavily laden with meanings that shift, expand and change. This thesis is an attempt to elucidate some of the associations attached to the cultural construction of disability among people in KwaZulu-Natal, many of whom are Zulu speaking. It sets out to understand the words, images, ideologies, myths and the metaphors that people associate with disability.

This study is essentially about conceptualisations of disability and HIV/AIDS. During the pre-research process two key questions crystallised out of the already available material.

1. How do people in KwaZulu-Natal interpret abnormalities or disabilities and how does this shape their reaction to and interaction with disabled people?
2. How do these interactions influence the exposure of people with disabilities to HIV?

My argument is that the cultural construction of disability and the living conditions people with disability face in KwaZulu-Natal puts them at high risk of infection with HIV. I argue in part, that people with disability appear neither to get appropriate sexual education nor sufficient support to protect themselves against HIV and AIDS. Disability is still mystified with notions that often lead to misinterpretation and discrimination. On the one hand this thesis attempts to 'unwrap' the world of disability and its connection to HIV/AIDS through:

1. Describing the cultural construction and representation of disability as well as HIV/AIDS.
2. Analysing the values, myths and meanings, including symbolic meanings attached to these constructions.
3. Discussing how the shared knowledge, meanings and symbolic representations shape the understanding of people with disability and attitudes towards them.
4. Arguing that these attitudes expose people with disability to HIV infections and that more disability sensitive sexual education and protection of disabled people is necessary.

On the other hand I will try to show that the empowerment of people with disabilities or their relatives changes their position in life. People with disability in KwaZulu-Natal have already created a system, called Community Based Rehabilitation (CBR), to support themselves. This community-based system should receive greater support from the official governing structures, especially financially, so that more support staff could be made available. This in itself would help to empower people with disability and with this decrease their exposure to HIV.

1.3 STRUCTURE OF THE THESIS

This thesis is divided into three parts. The first part introduces the reader to the context of this thesis. The second part deals with the conceptualisation of disability while the third part looks into the phenomenon of HIV/AIDS and its relation to disability.

Part I consists of chapters 1, 2 & 3. Chapter 1 provides the reader with some basic information about the thesis, while chapter 2 gives a general review of the current literature relevant to this thesis. As an anthropological contribution this thesis draws upon several different bodies of literature and follows an interdisciplinary approach. Chapter 3 discusses relevant methodological approaches and describes the research design for the fieldwork and the analytical work.

The parts thereafter will look at the construction of disability and HIV/AIDS from a macrocultural, microcultural and individual level (McElroy & Jezewski 2000, p. 192). This is necessary as both phenomenon are medical as well as socially constructed and this construction needs to be analysed on different levels of society.

Part II consists of chapters 4 & 5 and explores the phenomenon of disability in detail. Chapter 4 explores the macrocultural level and introduces the reader to the study site of KwaZulu-Natal. It provides an overview of the local culture and its historical roots; it explores the problems of finding an African identity in the 21st century and its effects on people in general as well as the immense gender imbalance that is still apparent in KwaZulu-Natal. The chapter also reflects on some facts and figures concerning disability in the province, in particular to clarify living conditions of people with disability. This is necessary to make the reader understand the setting that surrounds disability and HIV/AIDS in KwaZulu-Natal. Chapter 5 looks more into the microcultural and individual level of the disability experience and describes concepts of diseases and disabilities as found in the local culture. Thought patterns relevant to the way people view disabilities are also discussed. It explores the notions of supernatural (spiritual) and natural (body related) causes of disabilities. It also explains the strengthening effects of ancestral worship and a balanced lifestyle as well as the weakening effects of ´pollution´. In addition it is explained what role the interpretation process of disability plays in the treatment and inclusion or exclusion of

people with disability, the denial of exposure to education and the mystifying of disability.

Part III of the thesis, consists of chapters 6 and 7, which explore the phenomenon of disability and its connection to HIV/AIDS based on the research results. Macroculturally chapter 6 deals with some facts and figures on HIV/AIDS in South Africa as well as with the historical development of and the government response to the epidemic. On a microcultural level a large part of the chapter looks at the different notions that people have developed about HIV/AIDS and how they related to traditional notions about diseases. Here especially the concept of pollution as expressed through ´umnyama´ is discussed. The link between gender violence and HIV infections will also be explained.

In chapter 7 the problems of HIV infections for people with disability will be discussed on a microcultural level. On a more individual level this chapter will deal mainly with the practical relevance of the HIV/AIDS epidemic and the coping strategies that people with disabilities and their caregivers have developed. It addresses issues of overprotection, denial and empowerment and looks at the results of these strategies.

The eighth chapter of this thesis will summarise results as well as provide prospects for transformation. The analytical concept of McElroy and Jewzeski will reoccur here and provide the guidelines for the summarising analysis. The thesis closes with a personal reflection.

2 DISCUSSION OF PREVIOUS RESEARCH

Previous writers have observed the necessity for approaching the investigation into human behaviour from a holistic perspective (Albrecht, Seelman, & Bury 2001). The ability to draw established theories from other academic disciplines into the research is one of the most important factors in the study of disability. It is this approach that helps researchers to cast their investigative nets broadly, in an attempt to decode human behaviour and notions about phenomena such as disability or HIV/AIDS.

While literature about HIV/AIDS in southern Africa is plentiful, the field of disability still provides large areas to be explored. This chapter will discuss those parts of the current literature that help to analyse the relationship between the cultural construction of disability and HIV/AIDS in KwaZulu-Natal. It is written from a perspective that looks across disciplines and relates to different types of literature. The concepts of disease and disability are interlinked and therefore literature referring to both phenomena was chosen. In reviewing the literature relevant to this thesis the following bodies of literature will be discussed:

1. Studies on the social construction of disease and disability.

The first body of literature serves to locate this thesis within the field of disability studies and rehabilitation. It will focus particularly on the exploration of the historical development of different types of models about disability and their relevance for this thesis.

2. Psychological and anthropological studies on disease and disability

This body of literature includes studies on medical anthropology and social psychology and explains the origin and meanings of two psychological concepts relevant for this thesis: Subjective Theories and Social Representations.

3. Ethnological studies relating to KwaZulu-Natal.

The third body of literature reviews already known concepts about disease in KwaZulu-Natal and gives the ethnological background to the study site.

4. Studies on HIV/AIDS

The fourth review of literature relates to studies on HIV/AIDS and the cultural meaning of the disease.

5. Studies of sexual culture and gender studies on HIV/AIDS.

This body of literature deals with the construction of gender and its implication for the study of HIV/AIDS and disability.

6. Studies combining the problems of disability and HIV/AIDS.

The last body of literature will review those writings that have already explored the connection between disability and HIV/AIDS.

Historical views and current developments in the various fields will be explored alike as far as they can contribute to the topic of this thesis.

2.1 DISEASE, DISABILITY AND CULTURE

2.1.1 DISABILITY STUDIES

The beginning of the disability studies lies within the political movement of people with disability (Dederich 2007, p. 22). Its original purpose was to shift notions about abnormalities or disorders and press rights for people with disability. For a long time the disability studies created a front against the medical model of disability and contributed to the development of the social and cultural model of disability.

For most of history however, disability has not been viewed as a medical phenomenon. As close as the 17th century we find the discussions around the term “monstrum” and “monstrosities”, which referred to an abnormal, deformed body. As Moscoso (1995, p. 56) describes, the deformed newborn was seen as a sign of sin and ungratefulness in 17th century Europe. Moral misconduct represented itself as deformation and therefore the disability stigma affected parents and the person with the condition alike. Reviewing western concepts, Turner (2000, p. 9) writes that “beliefs about health and illness in traditional or pre-modern societies were inextricably caught up with notions of religious purity and danger”. These moral

notions were only lifted during the period of enlightenment in Europe (Dederich 2007, p. 90). In the ´enlightened society´ the notion of sin and moral misconduct were slowly replaced with a naturalised imagination of disability. The ´monstrosity´ or abnormality was not the subject of religious practice anymore but became the object of scientific interest and medical intervention (Dederich 2007, p. 91). Anomalies were seen with scientific eyes and not with theological or mystical ones anymore (see also Teratology). Scientists believed that they were replacing the pre-justice of the middle ages with scientific knowledge, metaphysical speculation with a rational picture of the world and myths with the truth. People wished to explain life on earth in a new way, therefore the scientific world undertook the huge task of structuring and classifying nature. In an attempt to place disability within a natural order, different classification systems evolved and categories of disabilities were developed. These efforts occurred within a general new definition of the world and an attempt to classify and structure nature. The monstrosity or abnormality represented, in this context, a deviation from the natural order (Foucault 2003, p. 76). Scientists, at the time, studied human bodies from the background of Darwin's evolutionary theories and Mendel's laws of inheritance. As a result, abnormalities as well as certain races were categorized as an in-between form of humans and animal (Dederich 2007, p. 95). Scientists of the 19th century found this theory very striking as it challenged old religious concepts of a strict separation between humans and animals. Some even hoped that by studying abnormality and race they were able to study human evolution as well. The perverse interest in the physical aspects of human nature at the time found its peak in the freak shows of the 19 century in Europe (Cook 1996, p. 140), where people with disability were displayed like animals in a Zoo. At the end of WWI deformations became "normal" and the sensational interest in "freaks" wore off (Cook 1996). The focus shifted from fascination to pity. Science and medicine shifted their interest away from assuming the role of spectator and recorder, towards a more rehabilitative view. Creating artificial limbs for instance became part of the medical profession. The deformed body was no longer an object of the open space but rather a symbol of loss and was hidden away. Medicine and Rehabilitation began to dominate the field of disability and a medical model was applied to disability in which abnormalities were categorized and appropriate treatment prescribed. People with disability got attributed passive roles where they were receivers of medical and

educational interventions, denied decision making, preventing them from taking their lives in their own hands and sometimes even denied the right to live at all.[3]

As a counter movement, in Great Britain, attempts were made in the 1970s to redefine disability (Dederich 2007, p. 29). In opposition to the medical or social-welfare model, which shows disability either in an individualised pathological sense or as an object of social welfare, the idea was developed that disability is actually a form of complex social oppression (social model of disability). Disabled people began to organise themselves in an attempt to protest against their coerced institutionalisation, their exclusion from the labour market and with this the denial to support themselves independently. They demonstrated against their forced dependence and the resulting poverty they had to live in (Thomas 2004, p. 32). Around the same time the political movement around people with disabilities in the USA was making similar progress. Now that a social science approach was eminent in the field of disability, so the focus shifted very quickly towards a more culturally orientated interpretation of disability (Mitchell & Snyder 1997, p. 10). The cultural model of disability was born.

About ten years later than in Europe and America, people with disability organised themselves in South Africa (DPSA 2001). The motivation was also of political origin as quite a number of people became disabled through the struggle years. What made the disability movement in South Africa unique in comparison to other disability movements was its involvement in a bigger class struggle against apartheid. As a result of this class struggle the social model of disability was adopted and is therefore still favoured in the disability movements in South Africa of which DPSA (Disabled People South Africa) is the biggest organisation (DPSA 2001, p. 11).

From a theoretical point of view the Symbolic Interactionism in the tradition of George Herbert Mead and Herbert Blumer contributed to the reinterpretation of disability. Fundamental in their perspective is the theory that people don't engage with the world directly, but connect the world with social meaning, structure it and react on the base of these interpretations to the world. Scientists that explain human behaviour with Symbolic Interactionism therefore imply that we live in a symbolical as well as in

[3] See here the elimination of people with disability in WWII and the Euthanasia debate around Singer in the 1990´s

a physical world. Life is a never ending process of attribution to our own as well as other peoples' actions and appearances. For this reason social science does not see the disabled body as an object, but rather as the result of cultural meaning and social attribution.

Extending this view, Albrecht points out that disability and the institutionalised answer of the Reha-Industry, is more than a social construction. The interpretation of disability does not depend only on economic factors, but is also a result of a cultural value system (Albrecht 2003, p. 43). He argues that individualism, capitalism and the American way of democracy provide the ground for the personalisation of disability. Disability in such a culture becomes a personal problem for which services are provided for on the free market. In opposition to many ´non-western´ societies disability has been attributed with mystical meanings. It is an issue for the whole group or extended family and involves everyone around the person with the condition. 'Treatment' could therefore affect people or objects other than the person with the abnormality. The social and cultural constructions of disability become eminent in this comparison and this is often used as an argument against the medical model.

Central to the discussion of the social and cultural model is the term stigma. It is often used, if not overused, and often understood as a negative attribution. In their cross-cultural study, Room and others (2001, pp. 252-256) summarise that stigma is differently attributed to various disabilities, however the research team concluded that in general the extent of the stigma depends on the cause and severity of the disability. Disorders associated with mental health conditions and addictions were, across cultures, the most stigmatised and people with these conditions were the least likely to receive adequate services or funding. On the other hand the interpretation of disabilities varied and stigma depended on this process. When a disability was seen as a curse from god or a sign of sin the stigma attached to it would be comparably large. A disability that was interpreted as an accident was much more likely to earn sympathy. Room, like others, is using the term stigma without giving it a precise definition, it is however important to explore its meaning (Room, Rehm, Trotter, Paglia, & Üstün 2001). Goffman (1963b; Room, Rehm, Trotter, Paglia, & Üstün 2001) in his sociological analysis of the term describes stigma as an attribute that triggers

social discrediting. The implications are a denial of privacy, only a superficial acceptance in a group and the perception as being a non-person. In the context of disability, stigma has also been widely discussed in the field of HIV/AIDS, as people with the virus experience substantial social discrimination and avoidance. Esses and Beaufoy (1994) found in their study that negative attitudes towards people with depressions or HIV/AIDS were more severe than the negative attitudes towards amputees. The element of control influenced these negative attitudes tremendously.

While the concept of stigma is relatively static, Murphy's theory of liminality opens a more flexible approach to the social model of disability. Murphy, himself a disabled anthropologist, published in 1990 his eloquent self-study of the disability experience. Among other things he linked the social experience of disability to the anthropological concept of liminality. Murphy understands liminality as the status of individuals that have not yet been accepted as a full member of society due to social restrictions. His construct is therefore more open to change and can also explain why stigmatising factors do not apply for all people with disability in the same way. For Murphy the permanent exclusion from life in its ordinary form and the denial to participate in society as a full member characterise the social experience of people with disability (Murphy 1990, p. 136). He therefore defines disability also as a "disease of social relations" (Murphy 1990, p. 4).

The social model of disability also argues that disability is a result of social oppression and discrimination (DPSA 2001, p. 12). However a weakness of the social model is its centralisation around the critique of the medical model. To some degree we cannot escape the fact that impairment is visible and objective. Within the medical model it is therefore easy to argue that impairment is not socially constructed as it is seen as a-historical, pre-social and just a natural fact. Hughes and Peterson (1997, p. 326) therefore argue that in the social model the Cartesian dualism of body and soul is still present. They therefore suggest that we see impairment as a medical problem, an individual experience and a cultural construction. Instead of concentrating on a general critique of society they base their theories on Foucault's discourse theorem of power and Maurice Merleau-Ponty´s phenomenology of the body. With this they managed to create a much more effective critique of the medical model. They are able to show that medicine keeps power over the discourse of

disability because this discipline holds the monopoly of naming dysfunctions. The body in this sense becomes the object of diagnostic labels, constraints and regulations. This power can only be challenged if common labelling is challenged.

Merleau-Ponty´s (1962) phenomenology of the body contradicts the common body and mind dualism. In this sense the body is not an object of but rather a subject of experience. This is embedded in a cultural system of meaning and perception. Embodied experience, of which disability would be one form, can therefore not be interpreted without the social and cultural system. So writes Merleau-Ponty simply "I'm my body" (1962, p. 180), and emphasises the strong connection between speech and body, which in his opinion can only be understood in connection to each other. The phenomenological view ranks speech secondary to embodied experience and sees speech as incapable of fully describing this experience. Merleau-Ponty sees the body rather as something that is sensible towards all other objects, something that gives resonance to all sounds, colours and words and something that gives all perceptions their original meaning (Merleau-Ponty 1962, p. 276). Therefore our world is always an embodied one that has already been interpreted. Exploring this thought more deeply Plügge (1967, p. 64) writes that "the body and the world around it will never be two different or dividable things. The world is only created through the body, in other words it depends on the existence of the body. The body therefore belongs to both at the same time: the self and the individual world". The last comment from Plügge also reflects that the body is not only a material object but also a social one. In other words the body has a social dimension which becomes visible to us when perceived by other people. This perception usually includes the interpretation and involvement of the body into a complex network of interactions, relationships, attributions and evaluations. Our self understanding develops on the base of social relations, self image evolves only in relation to the ´other´ (Foucault 1984, p. 72; Levinas 2004, p. 103). The other therefore holds a key position in the interpretation of body and disability for the disabled person, however the ´other´ is dependent on the way a person has internalised common concepts about body and disability. Discourses about nature versus culture, normal and norm as well as discourses around identity influences this position.

The differentiation between nature and culture is very important in the discourse about disability. Different models of disability give different importance to the two terms. Reflecting on this Waldschmidt argues that while the medical model reduces disability to the naturally visible fact: the impairment, the cultural model interprets disability as an historically and socially based construction (2003, p. 15). In this sense Baumann postulates his interpretation of social order as a central aspect of culture. He understands culture as an important part of order in human societies and a driving factor to differentiate between order and disorder, between normal and abnormal. Culture in this sense replaces or adds to the natural order (Baumann 2000, p. 200).

What is normal or abnormal? The discovery of the body as a medical object in the 19th century led to the creation of the ´norm body´. Criticism of the medical model is therefore not possible without exploring the terms norm and normal. While several authors don't keep the two terms apart (Davis 1995, p. 23), Dederich on the contrary gave us an applicable definition. Going back to sociological theory, he explains, that norms are legitimated through general social-cultural values. Social norms structure the expectations of people towards interactions with other people and make, therefore, the behaviour of people to a certain extent predictable. With regard to Foucault's theory he extends this view and presses the point that norms aren't only repressive, but that without them social interaction would not be possible (Dederich 2007, p. 130). In the philosophical field norm can be applied in four different ways:

- as an empirical average,
- as an idea or term (norm as border setting),
- as a technical parameter,
- as a juristically set up and moral value (Höffe 1992, p. 200).

The conceptions about normal or normality on the other hand are set through comparison. Being normal is a construction of thought. While norm has a juristic trend to determine where the line lies between right and wrong, wanted and unwanted, the term normal and normality imply descriptive categories. Norms are set from outside and can vary in different cultural settings. Normality is based on comparison. It is that which falls in the middle of a Gaußchen distribution (Dederich

2007, p. 134). In relation to this Link (1997) presses the point that norms and what is perceived as normal can contradict each other. He explains through the example of abortion how the religious, moral and juristic norm define exactly if abortions are acceptable at all and if so, when. The acceptance in the public eye can differ tremendously from this and sometimes even initiate a discussion towards a change of these norms (Link 1997, p. 22). Normality is strongly connected to the way we draw boundaries, which is either, in the case of ´norm´ a strict juristically drawn line or in the case of ´normality´ a flexible line, which depends on peoples' perception of the average. While norms can easily be exposed as setting boundaries and discrimination, the concept of ´normality´ is more complex and can't be separated from the social and cultural context. In this context, particularly, Foucault's (2000) theory of Governmentality explains this flexible normality as a particular political strategy that mixes individual and social coping strategies. In such a perspective, normality will be perceived by the individual as an internal value of what is ´normal´ in his society. This normality will influence the individual's perception of the environment and how he or she acts. Therefore ´normality´ has huge power over the individual. In Foucault's theory power is therefore not an outside influence forced onto the person. It is far more a form of internalisation that dominates internal regulation mechanisms and with this perception, knowledge and behaviour. Through internalisation ´normality´ becomes a self-regulating power. Abnormal in this context is the contrasting term of normal. Even though both terms are relative they are often used as absolute and discriminating, however they are also used as a descriptive term in the disability studies. For instance Neubert and Cloerkes (1994) use this term in their book to illustrate the relativity of abnormality and how different cultural settings react differently to abnormally perceived conditions.

In the last 20 years two different ways of handling normality have evolved. The movement around 'normalisation' tried to show disability as part of humanity and insisted that people with disability should live a life as 'normal' as possible. On the other side of the spectrum the biomedical field developed a "proto-normalisation" in which the prenatal diagnostic played an important role. The human body was once more pressed into norms and anybody with a disability that placed their body outside of these norms was not considered worth living. The two trends visible up until today. While we see more and more people with disability in public places, schools and at

work, we see fewer and fewer people with Down-Syndrome as a pregnancy with a Down-Syndrome child can be terminated even late in the pregnancy term.
In the last three decades the above mentioned discourses have caused a major shift in the conceptualisation of health and disability. The focus has shifted from the medical approach that focused on diagnosis and therapy to a broader approach that also includes the social causes of disability. In recognition of this change the World Health Organisation (WHO) initiated a cross-cultural research study (Üstün et al. 2001) that developed a picture of the functional aspects of individual health experiences (see model in chapter 5) and a classification system now known as the ICF[4]. Health and disability in the ICF are understood as an outcome of interaction between features of the person on the one side and the social and environmental factors on the other (Üstün et al. 2001, p. 8). Experts and people with disability alike agreed in the WHO model to see disability as a complex phenomenon with its biological, psychological, cultural and social factors. A certain feature (like red hair or cerebral palsy) can cause different reactions in different cultural settings and therefore what might cause disability in one context might not do so in another. However even this international model of disability from the WHO is still influenced by the concept of normality as the description of disability is not possible without this term.

Preceding this development were ethnological studies that tried to understand the cultural dimension of disability. Cross-cultural analysis has shown that negative attitudes towards disability differ and that medical classification can not sufficiently explain the disability experience.

Analysing disability-related research, which was conducted in various countries, Neubert and Cloerkes (1994) created in their classical work the concept of "Andersartigkeit" (abnormalities). Abnormal in their understanding can be anything that will fall outside of the previously discussed normality as long as it is also attributed with cultural meaning. Their cross-cultural study explored social reactions to "abnormal" features and compared these reactions in relation to their cultural background. Neubert and Cloerkes (1994, p. 50) understand disability as a negatively interpreted "abnormal" feature. Through their analysis they identified 7

[4] ICF – International Classification of Functions, Disability and Health

different types of reactions to disability. They labelled them as active killing, exclusion, isolation, partly/reduced participation, modified participation, laisser-faire and emical normalisation. Neubert and Cloerkes discuss how stereotypical reactions to certain features impact on peoples' lives. Through these a person would experience disability. Disability was interpreted as a social construction. Comparing 24 cultural studies, Neubert and Cloerkes identified 7 patterns (1987 p. 88 ff), which they claimed to be valid in all the cultures that they studied. They found severe impairments to be universally negatively evaluated in all cultures, a similar result was found by Üstum a few years later (Üstün et al. 2001). Extreme reactions like exclusion or killing were only reported in the case of people with very visible and severe impairments. Social reactions to ´abnormal´ features varied within different cultures (inter-cultural), depending on the cultural interpretation of that feature. Within one cultural context (intra-cultural) reactions were found to be uniform. Diverse reactions to the same impairment within one culture were seldom found, a fact that I will argue to be very different in the current trend of globalisation and cultural diversity.

Neubert and Cloerkes (1994, p. 87) criticised themselves that their work provides only unsatisfactory explanations about the interpretation of abnormalities and the resulting reactions. Although they were able to explain under which cultural background which notions and reactions to abnormalities were common, they could not explain how people developed these notions. The link was missing.

Other authors who explored the social attributions to disability likewise did not theorise as to where these attributions come from. Usually certain elements of these attributions, for instance the curse of god, are mentioned but the exploration into the field remains descriptive. Room and his co-authors (2001, p. 262) show in their in-depth study for the ICIDH-2[5] version that attitudes about "etiology"[6] and presumed causal history determine societal attitudes towards disability and programmes of assistance. They particularly explore the problem of awareness and conclude that the threshold of noticing a condition, as well as the threshold of identifying disability, are culturally related. The study, very convincingly, concludes that stigma is attributed to disabilities and drug abuse. It also describes intellectual disabilities and

[5] ICIDH – International Classification of Impairment, Disability and Handicap
[6] etiology – US spelling of Aetiology – set of causes or manner of causation of a disease or condition

drug abuse as the most stigmatised across cultures, however the study does not fully analyse the hidden meanings, attributions and subjective theories that cause the stigmata or discrimination. Room (2001, p. 276) only explains the attributions for severe stigmata in the case of drug abuse and HIV/AIDS infection, as these are attributed with personal guilt. In other words people with HIV/AIDS and drug addicts are seen as responsible for their situation. People therefore have less sympathy and understanding for them than they would have for a person who became disabled through a car accident. Room (2001, p. 256) also briefly mentions the notion of a cursing god and sin as a cause for disability. These two facts are the only part of the study where hidden meanings are more deeply explored and described. Besides that the linking process between the threshold of awareness and the interpretation process of the abnormal feature are not further explored. For this purpose I will use literature from the field of Medical Anthropology and Social Psychology.

2.1.2 MEDICAL ANTHROPOLOGY AND SOCIAL PSYCHOLOGY

The above mentioned link between the threshold of awareness and the interpretation process of the abnormal feature can better be explored with techniques used in the field of Medical Anthropology and Social Psychology. Originally researchers in both fields tried to understand common notions about diseases and their relations to cultural norms, traditions and practice. Studies in Medical Anthropology inquire into the culturally related interpretations of diseases and try to explain the cultural and subject related roots of individual health-belief models (HBM), while the field of Social Psychology explores more how the individual is influenced by cultural concepts and social settings.

Medical Anthropology is a sub-branch of Anthropology. It, however, finds its roots not only in the classical social and cultural approach of anthropological studies but also within medicine and other natural sciences. Medical Anthropology is about the ways in which people in different cultures and social groups explain the causes of ill-health, the types of treatment they believe in, and to whom they turn for help if they get ill. In Foster and Anderson's definition it is: "A bio-cultural discipline concerned with both the biological and socio-cultural aspects of human behaviour, a discipline particularly concerned with the ways in which the two interacted throughout human history to

influence health and disease" (Foster & Anderson 1978). Almost all anthropologists exploring the field of health pointed out that in human societies, notions and practises relating to health and illness become a central aspect of the local culture. In this context Helman (1994, p. 7) suggests that the notions of diseases and illnesses are often linked to a wider range of beliefs about misfortune. In some societies these misfortunes are blamed on supernatural forces, a divine retribution or the interference of a witch or sorcerer. Fascinated by the exotic character of such cultures anthropologists began to investigate the notions and meanings of health and disease.

The first enquiries into this field were made by researchers and missionaries that explored these 'exotic' cultures. These studies are therefore closely related to ethnology. Three Anthropologists are seen today as the classical writers of ethnological medicine. William Halse Rivers (1924) was the first anthropologist who tried to understand the culturally related theories about disease from an emical[7] perspective. He identified in his book Medicine, Magic and Religion three "world views", namely "magical", "religious", and "naturalistic" and described the imaginations about disease and treatment based on those views. His own biomedical approach[8] was exempted from this analysis. He pressed the point that "however wrong the beliefs of Papuans and Melanesians concerning the causation of disease are, their practices are the logical consequences of those beliefs" (Rivers 1924, p. 29). Although this statement may seem to be quite arrogant, he had at the time acknowledged the influence of the disease interpretation process and its logical consequences thereafter (attribution and reaction). Another classical writer is Clements Forest with his thesis *Primitive Concepts and Disease* (Clements 1932). He identified five attributes of disease: witchcraft, spirit intrusion, soul loss, disease-object-intrusion and taboo breaking. Forest and Rivers described the medical systems as separate from each other, while Ackerknecht (1971) integrated them into a bigger social system that is interlinked. This was an important step at that time. Ackerknecht as well as his predecessors described foreign medical systems as "magical and religious" and therefore not rational and scientific. Early anthropological writings on culture and medicine shared much of the embarrassing evolutionary language of other disciplines. Medical ´beliefs´ and practices of ´non-Western´

[7] emic - insider view, being the opposite of ethical, which is the ´outsider view´
[8] This is often referred to as "western" medicine

people were often interpreted as early stages of medical knowledge. Enlightenment convictions about the advance of medical knowledge run deep, and although change is visible, medicine is a domain in which “a salvational view of science” (Geertz 1983, p. 146) is still a great force.

Modern, ‘western’, medical intervention is often compared to so-called ‘traditional’ interventions. The first is often described as modern, rational and based on knowledge and the latter as superstitious, irrational and based on beliefs. Striking is the polarisation of knowledge and belief. Good (1994, p. 20) recognises that there is little analysis of the history of the concept of ‘belief’ in anthropology and questions the notion of belief. Belief is seen as something that can be wrong and irrational, while knowledge claims to be the truth. Based on this interpretation anthropological research using the term ‘belief’ is judgemental and seems inappropriate. The famous Zulu shaman Vusamazulu Credo Mutwa criticises, and not without reason, that only very few white people have a clear understanding of African people, because “white people have never bothered to study the African people carefully” (Mutwa 2003, p. xxix).

Medical anthropologists as well as psychologists and sociologists in the field have been fascinated by so-called “exotic cultures” as well as “Lay concepts of disease” and try to understand why people often prefer popular imaginations and notions about diseases instead of explaining disease with a biomedical notion of science. Moscovici (1995, p. 268) even speaks of “feeling an uneasiness” by realising that the only intelligent being on earth, “homo sapiens”, appears as such an unreasonable being. He was fascinated to study how quickly and easily unscientific rumours can be spread. This is particularly interesting, if one considers the phenomenon of HIV/AIDS or disability. Since we do not imagine human behaviour to be completely unreasonable, there is a need to explain the phenomenon of religious and magical notions, popular and general thoughts and ideologies as well as behaviour in groups.

Recognising a wide spectrum of illness and disease definitions, and the fact that professional criteria differ from lay concepts, anthropologists find it helpful to distinguish between illness, disease and sickness. McElroy and Jezewski (2000, p. 191) define disease as the “deviation from a biomedical norm”, illness as the “lived

experience of cultural constructed categories" and sickness as "a patient role". The differentiation of illness and disease seems to be used continuously by anthropologists, while the term sickness occasionally appears, as for example in the classification by Kleinman and Seeman (2000, p. 231). While disease is a central focus of biomedical practitioners, factors affecting illness and sickness, and the transformative power of illness and disability, are more pivotal concerns for the social scientist.

Medical Anthropology tries to explain human notions and actions towards health with cultural influence. Jezewski defines culture as "a system of learnt and shared codes or standards for perceiving, interpreting, and interacting with others and with the environment" (McElroy & Jezewski 2000, p. 191). Using their model, cultural influence can be studied on different levels: the macrocultural, the microcultural and the individual level (p. 192). Illness and disability experience cuts across all three levels. The cultural understanding of illness and abnormality can differ markedly between people in different social positions (e.g. patient and doctor), educational backgrounds as well as social and cultural groups. Hellmann (1994, p. 10) illustrates in the example of oral dehydration therapy in Pakistan, how contradicting concepts between patients and health advocates can effect the intervention strategies to serious epidemics. The study in Pakistan reflects the importance of addressing medical concerns as well as involving the affected community and understanding of local culture. In the previously mentioned study in rural Pakistan mothers tended to ignore the Oral Rehydration Therapy (ORT) while their children got seriously sick through diarrhoea. The mothers did this despite the fact that the use of ORT was widely promoted and freely available. Through an anthropological approach scientists found out that diarrhoea is interpreted by the local community as a natural and expected part of teething and growing up and not as an illness. Some mothers were even convinced that it was dangerous to stop diarrhoea as "trapped heat" would otherwise spread to the brain and cause fever. Others explained diarrhoea as a folk illness caused by evil spirits, which can only be treated with traditional remedies. In general diarrhoea was seen as a ´hot´ illness, which required a `cold´ form of treatment. As Western medicine, such as antibiotics, ORT and vitamins, are classified as ´hot´, they were therefore seen as unsuitable for the diarrhoeal child. Similarly the importance of a cultural understanding of epidemics has been

particularly and often described in the context of HIV/AIDS (Helman 1994; McElroy & Jezewski 2000; Whiteside, Mattes, & Willan 2002). This cultural understanding can help to provide more effective interventions through the reductions of misconceptions.

Building bridges and forming understanding between different groups is described by Jezewski as “cultural brokering” (Foster & Anderson 1978; McElroy & Jezewski 2000, p. 193). In this theory problems, strategies and resolutions are adjusted to create understanding and successful strategies for intervention. Researchers in this context always underline the point that it is important to understand local cultures within their own medical classification system. Several anthropologists have tried to develop a classification system that categorises different approaches to health, disease and illness. One of the often quoted classifications is Turner’s typology of domain assumption. Turner (2000, p. 11) argues that health concepts can be analysed along two dimensions: the sacred/profane and the collective/individual orientation to health and illness. The categories of sacred and profane can be compared to the classification of natural/unnatural causes of disease that other researchers have established (Ngubane 1977).

	Sacred	Profane	
Individual	Saintly Sickness	Allopathic Medicine	
Collective	Sickness Taboos	Social Medicine	

Feature 2-1 Typology of domain assumptions, Turner 2000, p. 11

Illnesses that are explained with a sacred or unnatural cause are often those diseases that are attributed to divine punishment, evil spirits or sorcery. Thus the suffering person, a family member or a witch can personally be held responsible for the misfortune. Alternatively human illnesses explained with profane or natural terms is usually explained with the presence of germs, viruses or accidents for which the individual cannot be held responsible. Turner’s dimensions of individual and collective explanations of illness reflect the attribution of disease on a personal or social level. The individual/secular concept forms the basis of allopathic medical

approaches of empiricist Cartesian medicine. Disease in this context is caused by malfunction of the human body. Individual interventions are seen as necessary. On the contrary, the collective model attributes human suffering to social causes, for instance the deprivation and alienation in working class slums (Turner 2000, p. 11).

While Medical Anthropology has contributed predominately in a descriptive and categorising way, the field of Social Psychology has developed some useful theories about the origin of socially dominant notions on illness. Social Psychology therefore studies, more closely, the cultural effects of illness. The ideas of Subjective Theories on health and disease as well as the idea of Social Representations (Moscovici 2001) have the ability to deepen our understanding of the individual and societal understanding of diseases.

Moscovici first introduced the theory of Social Representations in 1961, after he analysed the reception of psychoanalysis in France during the 1950^{s} (Moscovici 1995, p. 272). The theory of Social Representations is unique because it tries to combine a general theory of social life with a specified theory of individual psychology, a link that only the psychoanalysis is able to make. Moscovici based his theory on Durkheim's concept of individual and collective representations, on Freud's psychoanalysis and on developmental theories from Piaget (Durkheim 1968 / 2005; Piaget 1969).

Influenced by Durkheim's concept of collective representations and driven by the goal of explaining the "irrational" behaviour of "homo sapiens" Moscovici (1995, p. 272) began to understand knowledge and ´belief´ systems as a power that binds people together and which has the capability to activate passive members of society. He understood them as necessary to maintain the social way of living in a society and to pass on values and norms to the younger generation. In this way he disagreed with Durkheim, who interpreted everything cultural just as a naïve notion and misconception (Moscovici 1995, p. 274). However, Durkheim introduced, with his anti-thesis the idea, that people acquire their knowledge and thought categories from society, a radical change in Sociology and Anthropology at the time. In his original work he explains, that according to human perception and in an attempt to add other representations of reality to the individual interpretation, one had to develop a new

way of describing this phenomenon – “the collective thinking or representations” (Durkheim 1968 / 2005, p. 340). Elsewhere he argues that a human being, which does not think in such concepts, is not a human being as it would not be a social being. It would have to depend on its perception only and this would be not very different from an animal (Durkheim 1968 / 2005, p. 519).

In this context Moscovici argues that one should pay less attention to the collective character of these representations and rather explore the “mental life” of these imaginations more deeply. Here Moscovici (1995, p. 276) mentions three pillars, that formed the background to his theory of Social Representations: the preference of representations or common beliefs as an explanation, the social origin of these representations and the occasionally absolute role of these notions. He argues that beliefs, in Durkheim’s sense, are only perceived as irrational when measured against the physical world. In other words, if a person idealizes a plant or animal he is seen as a victim of illusions. If however everyone recognises this plant or animal as a symbol, the notion about it becomes reality and this is the phenomenon Moscovici describes as social representations (Moscovici 1995, p. 279).

To study these representations further, it was however necessary at the time to initiate comparative research of myths, legends, traditions and language so one could better understand how representations are interlinked or oppositional to each other. Levy-Bruhl (1951) seems to have been the first person to have undertaken the attempt to compare different cultures and their collective representations. Placing emphasis on cultural differences and interpreting Levy-Bruhl’s writing, Moscovici (1995, p. 282) postulated four aspects of collective representations:

1. Representations are always holistic, thoughts and representations are always a sum of previous thoughts. In other words, knowledge and beliefs can’t be attributed to a particular individual or group, they are always embedded into a network of notions and thoughts.
2. Representations are intermingled with emotions and particularly in so-called “primitive societies”. Therefore these representations do influence the affective bonding and interpretation of the object that the representation is about (Levy-Bruhl 1951, p. 26).

3. Collective Representations include general belief systems and ideas which affect general practice in and perception of the world.
4. Collective Representations are equally coherent and important, there is no ranking between them.

One might not like Levy-Bruhl's terminology of "primitive cultures", a term he used for cultures he found ´exotic´, but one has to see his work in its historical context. While scientists in the 1920[s] were still able to work with the term evolution, particularly with the evolution from primitive to civilised cultures, this was no longer possible after Levy-Bruhl. Levy-Bruhl also analysed the differences between the so-called "primitive" and "civilised" cultures in precise detail. Particularly impressive at the time was his ability to analyse the connections between religious or ritual behaviour and certain sayings, word phrases, number systems and the behaviour towards the sick or dead. In a summarising conclusion he postulates that collective representations in "primitive cultures" are less scientific and more emotionally attached as in "civilised cultures". Social memory is, in these cultures, of more importance and the people using these representations have fewer problems with contradicting elements within their personal theories (Levy-Bruhl 1951, p. 79). At the time this was a boundary breaking discovery and Levy-Bruhl's theories therefore influenced people like Piaget and Vygotski[9].

While Levy-Bruhl and his contemporaries used stories from adventurers and missionaries in exotic cultures, Vygotski and Luria[10] made an effort to explore the theory of collective representations within their own culture. The two Russian psychologists chose as their study field nomads in Uzbekistan and Kirgisien. In particular Luria hoped through the nomad population he would be able to study the changes, forms and contents of human thought, as these people lived at a nexus between traditional and modern culture (Lurija 1993, p. 74). However their theory also uses terms like "scientific" and "unscientific" representations and devalued the so called "unscientific culture".

This is exactly where Moscovici's critique of collective representations is positioned. He argues that the "norm" presented by scientific approach and the over-generalised

[9] Vygotsky – German spelling Wygotski
[10] Luria – German spelling Lurija

logic connected to this stigmatises and devalues, automatically, other forms of thought and belief (Moscovici 1995, p. 294). He criticises, that without further explanation, societies are either categorised as scientific or unscientific and collective representations are only studied in ´unscientific´ cultures. Besides this, collective representations are seen as characteristic of ´total´ or enclosed societies in which symbolical and practical relationships between individuals are completely integrated. In such a society all behaviour seems to be guided by mythical and ritual traditions (p. 295). The representations are described as being a general understanding of a social group and very static. Moscovici argues that collective representations can therefore only be applied to very “exotic” or historical societies. They are typical for societies in which institutions, language and traditions rigidly represent the belief system of all individuals. Moscovici therefore created, as an alternative to such a rigid concept, the theory of Social Representations and summarises under this term any form of belief, ideology or knowledge. They are for him the quintessence of Social Representation, which in return are applicable to any cultural background (Moscovici 1995, p. 298). Ordinary knowledge that people apply in daily life can be used to study these Social Representations (1995, p. 302).

Social Representations are generally understood as reflecting social knowledge that has evolved in a particular social group. Another aspect of it is the expectation that knowledge in general depends on belonging to such a group and that this determines what people know and how they know it. Flick writes in this regard that Social Representations don’t just reproduce reality. Moscovicis model is constructive in two ways. Firstly the model implies that reality as such does not exist as it is always constructed through interaction between individuals and groups. Secondly the process of Social Representations itself is a method to construct reality (Flick, Kardorff, Keupp, Rosenstiel & Wolff 1995, p.74).

Traditionally Social Representations are described as a system of values, ideas and behaviour descriptions. Flick (1995, p. 14) mentions two functions. On the one hand Social Representations help the individual to structure and organise their environment. Moscovici himself presses the point that Social Representations have the purpose of creating a bridge between the known and unknown (1995, p. 307) so the individual can orientate itself quickly in its environment. On the other hand Social

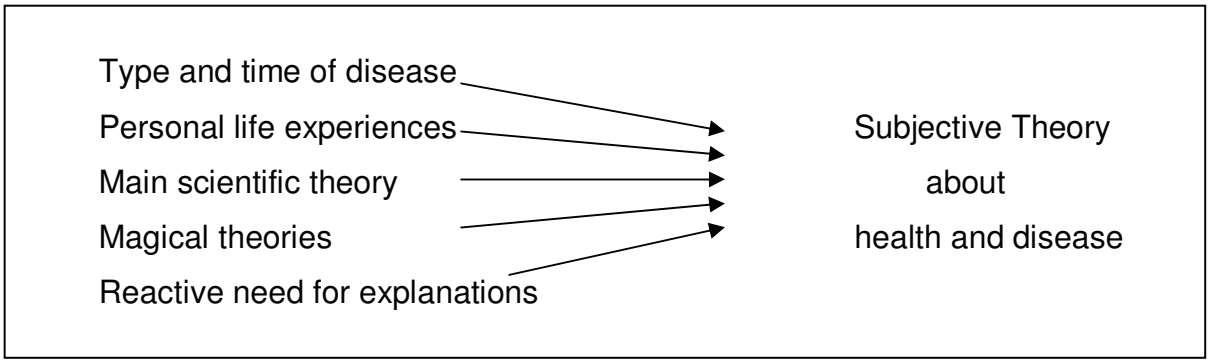
Representations make communication between group members possible in the first place, as they provide a code for social exchange and a code for labelling different aspects of the world. In other words the purpose of Social Representations is to make communication within a group relatively conflict-free (1995, p. 309). Therefore Social Representations don't simulate reality but they influence our perception and interpretation of it (Moscovici 1995, p. 311). At this point however it is interesting to see how previous writers explained how the mechanisms of Subjective Representations work within the individual and how a person constructs his or her understanding of the world and how this shapes the person's understanding and imaginations about disease and disability. The concept of Subjective Theories seems to be most helpful in this context.

Flick (1998, p. 12) describes subjective imaginations about health and disease as determined by gender, age and individual health conditions. The cultural dimension described above could be added as a fourth factor. Depending on these factors a person is believed to develop an individual theory about health and diseases. These theories have different purposes and are summarized as Subjective Theories. In general Subjective Theories are understood as an aggregate of thought to interpret the self and the world. These thoughts appear in an argumentative structure that is comparable but not identical to the structure of scientific theories (Groeben & Scheele 1982, p. 16). Through Subjective Theories the individual becomes an expert in a field, which enables the person to quickly analyse a situation and find orientation (Flick 1998, p. 14). They also provide an explanation for disease and help predict future events.

Raspe and Ritter (1982, p. 1202) conducted research on patients with chronic polyarthritis and found that most of their patients had a combination of explanations synthesised in their Subjective Theory about their disease and Raspe and Ritter called these types of theories "Mosaic theories". It is very likely that in the time of globalisation these "Mosaic theories" will occur much more often and will become more diverse. This also argues against a dualistic picture of so-called western versus traditional medicine and speaks for a more pluralistic approach as seen in Becker's (1986) model. His model incorporated theories about culturally related interpretations of disease, the influence of individual situations and the life experiences of a person.

All these points are combined in Becker's understanding of the evolution of Subjective Theories.

In Becker's model it becomes apparent which factors contribute to the development of personal theories about disease and disability. People will only start to look for an explanation for a disease, abnormality or disability if they have a need to explain it. The threshold of an abnormality influences this to a large extent. In a second step the personal life experience of the individual plays a major role in the interpretation process. In accordance with the person's knowledge about science or magic, interpretations of the disease or disability are developed. Within a cultural group one can often identify reoccurring interpretations of diseases and disabilities.



Feature-2.2 Subjective Theories about diseases (Becker 1986, p 318)

Moscovici's (1995, p. 309f) concept summarises these "repeating notions" of disease as Social Representations. In Becker's model they are reflected as the ´main scientific theories´ and the ´magical theories´. These representations form a so-called "Health-Belief Model" (Moscovici 1995) on which individuals or a whole cultural community will base their knowledge and decision making. Scientific research tries to identify these Social Representations and hopes through them to explain how people make sense of their experiences and life circumstances.

A theory linked to the two theories mentioned above is the theory of Social Attribution. Attributions are assumptions people make about characteristics of humans or objects and the causes of phenomena around them. Hewstone and Augoustinos classified two types of attributions, the personal and situational attribution (1995, p. 79). Personal attribution relates to internal causal factors like the disposition of a person, while situational attribution refers to the external factors that are caused by the situation and environment a person finds themselves in. The

authors press the point that people in general tend to overestimate the personal causal factors, while underestimating the influence of the environment. The two authors have however written the last statement from a western perspective and it is therefore possible that in another cultural context people could attribute more meaning to the situational factors. What Hewstone and Augostinos have postulated is the inter-relationship between attribution and Social Representation (1995, p. 81). Social Representation is understood by them as the basis on which a person builds attribution. In other words Social Representations explain the origin of attributions, the link that for instance Neubert and Cloerkes did not explain.

The models of Social Representation and Subjective Theories can help to reinterpret work from other scientists. One such example is Ngubane's findings about the Zulu health belief system. Based on their subjective interpretation of illness and disability Zulu-speaking people in KwaZulu-Natal differentiate between natural diseases and diseases of African people (Ngubane 1977, pp. 23-24). Natural diseases are cured purely with medicine which is believed to be potent in itself. Therefore, for those types of diseases, people accept curing techniques and medicines of the so-called "western type". For "diseases of African people" they will only accept "traditional medicine and advice". Ngubane (1977) identified for the Zulu disease "belief system" 5 main causes of disease. Diseases are therefore either classified as caused through natural influence, sorcery, ancestors, pollution or evil spirits. As these concepts seem to be widely spread, they can also be classified as Social Representations. These Social Representations influence the Subjective Theory of an individual in this particular culture. Depending on the interpretation of the illness people will choose different specialists and treatment. One and the same phenomenon can therefore be treated differently, regardless of the visible symptoms. With the classifications of the biomedical model different diseases can be treated with similar medicine and rituals, if the cause is believed to be the same. This might be classified as irrational behaviour from an ethical point of view, but it appears to be completely rational from an emic perspective.

From a biomedical point of view irrational patient behaviour can be explained through the person's individual or Subjective Theory of health and disease. Cassel (1955, p. 29ff), who conducted research with a Zulu tribe, describes for instance a disease with

pain in the breast region, breathing problems, coughing and bleeding sputum, all of which was attributed to the effects of witchcraft. Special medicine was provided by the local sangoma. Before the colonial era this disease was probably pneumonia and during colonisation tuberculosis was introduced, which had very similar symptoms. The colonial doctors could not understand why the indigenous people did not come for treatment and rather chose the local medicine, which was regarded as primitive. Understanding their interpretation of disease and how it is related to sorcery and witchcraft, one can understand why these local people did not see any need to consult a colonial doctor, who had no expertise in these matters anyway.

Bringing more clarity into the picture, Ngubane (1977, p. 30ff) describes sorcery as a deliberate placement of "harmful substances in situations which can harm particular people". The intention is the crucial point that labels an act as one of sorcery. Africans believe that non-Africans do not understand the notions of health and disease and causations of diseases that are based on their cosmology. Disease or misfortune caused by sorcery would be one of these. Therefore an African medical practitioner or so called "traditional healer" would be the only person to be consulted (Ngubane 1977, p. 24).

These cultural discrepancies about health and disease have been carried forward into the present day. International institutions like the WHO[11] define health as physical, psychological, mental and social well-being (WHO 2002). The human body is described as something that people can look after and is seen as being separate from the person's soul. A person is believed to have one soul. This separation of body and a single soul is a typical concept of cultures influenced by the three main religions. The mental/psychological level is usually given a higher value than the physical one. People will look after their bodies as a king looks after his subjects. Mistreatment leads to revolution and strike, in this case disease. This concept is contradictory to African interpretations of disease such as Gronemeyer (2002, p. 28) found in Namibia. In his study participants experienced themselves as one with their body and not the body as something they have to look after. Therefore they saw themselves incapable of looking after their body like a biomedical model would suggest. The Zulu shaman Mutwa on the other hand describes that his people have

[11] WHO – World Health Organisation

two souls the “ena” and the “moya”. One symbolised the “fight” between good and bad in every human, which is believed to be balanced out in a healthy person. The other one being “the self” made out of a spirit substance, that is in contact with the “other world” and the ancestors through dreams (Mutwa 2003, pp. 18,19). This notion is also difficult to include in the WHO model or any other bio-medically based models.

Notions about disability and disease in KwaZulu-Natal are today based on a variety of concepts or Social Representations. Ntombikile and Mazibuko (1989, p. 104) interviewed parents of children with cerebral palsy (CP) in KwaZulu-Natal and found that those parents had looked for help using a mixture of professionals, like doctors and nurses in hospitals, faith healers, and traditional as well as spiritual healers. As a consequence parents were often confused about the mixed messages they received. The two researchers therefore noticed misconceptions about the child’s problems and abilities. For instance, quite a number of mothers imagined their child to be “mentally retarded”, because it had CP[12] (Mazibuko 1989, p. 101).

Conducting research into mental health care in the same province, Mkize (2002, p. 5ff) found that many people don’t pass through the filters of national health care as they would not consult a doctor but rather attended a spiritual healer. Disorders therefore often took a long time to be diagnosed by the public health system. The decision to contact a doctor was in most cases influenced by the seriousness of the illness, availability of health services, financial implications and personal factors. Mkize (2002, p. 51) explains that if bewitchment or “ukufa kwabantu” was suspected there would be a delay to seek “relevant mental health care”. She pressed the point that the “belief system” of sorcery as identified by Ngubane (1977) is still entrenched in the way of thinking and the lifestyle of the African people (Mkize 2002, p. 54) and therefore influences the choice of treatment immensely. Writings on these notions shall be reviewed in the next body of literature.

2.1.3 ETHNOLOGICAL STUDIES ON DISEASE IN ZULU CULTURE

Zulu ethnography and recent history is well documented. Travellers, traders, government officials and above all missionaries have been adding to this literature for

[12] CP – Cerebral Palsy

200 years (Schimlek 1953; Steward & Malcolm 1986). Usually social life, custom, cloth and literature are among the researched subjects. Disease is, except for Ngubane's work in 1977, a subject usually mentioned in passing. Not surprisingly there are hardly any studies to be found that discuss the cultural interpretation of disability.

Beside Social Psychology, anthropological and ethnological studies also explore subjective health theories or so called "health-belief models" (HBM). The Ethnography study by Ngubane (1977) shows how Zulu speaking people interpret health and disease and how they presuppose a conception of human nature and the human life cycle as part of a totality that can best be designated as the "Zulu-cosmos". Without this background the characteristic Zulu procedure in the treatment of illness, prophylactic medication and disability cannot be understood. Her analysis of the significance of emetics for the physical and spiritual purification, that is basic to Zulu medication, shows the rationale behind their beliefs about contagion and of mystical affliction. Even so Ngubane does not mention disability, concepts of disease might be comparable. She mentions four major concepts that explain causes of diseases being either natural causes, sorcery, ancestors and pollution (1977, p. 22 f).

Ngubane (1977, p. 48) describes a case in which a young man married and took his genitors name against the advise of all his relatives and without involving his ancestors in the process. As a result he lost the protection from his ancestors and he and his children became sick through witchcraft. Her example shows clearly, how interlinked the notions about disease are for Zulu speaking people.

Studies of other cultural backgrounds show similar intermixtures of concepts. Referring to Evans-Pritchard´s (1937) work, Good describes the cosmology of witchcraft of the Azande using the example of a granary collapsing. "Every Zande knows that termites eat the support (of the granary) over the course of time and that even the hardest wood will decay after years of service". This explanation is however not sufficient for the Zande, as it does not answer why the granary collapsed at that particular time and affected those particular people. Good explains that although practical reason explains the immediate causes of the misfortune the Azande manage to answer the "Why me?" question with witchcraft (Good 1994, p. 11).

Another example shows how the Social Representations can influence people's decision making and get them to take action. Ngubane describes a boy's illness that was believed to have been caused by angry ancestors. They demanded that a sacrifice be made for having brought the father's wife into the family. "The baby was ill because the ancestors were asking who the mother of the twins was. The diviner stressed that the medicines she was giving him to cure the illness would have no effect unless Gwala (the father) made peace with the ancestors by admitting guilt and promising to put matters right as soon as he possibly could." A goat was slaughtered for the ancestors combined with an appropriate ceremony (Ngubane 1977, p. 49). The diviner's Subjective Theory about the disease led to a combined treatment that was based on herbal as well as spiritual treatment. This is something that is seldom found when using the biomedical model. Ngubane, however seems to describe a relatively pure culture that has not as yet been overly influenced by other medical models. These types of cultures are no longer likely to be found, other than in very remote areas.

Since her survey 30 years have gone past and KwaZulu-Natal has gone through some major changes. Nevertheless the "belief system" as identified by Ngubane (1977) is still entrenched in the way of thinking and the lifestyle of the African people. African concepts still exist and have mixed with other interpretations and today we find a variety of concepts and approaches. People choose healthcare, depending on their individual interpretation of the disease or disability. Interpretation and treatment of disability is therefore highly dependent on people's choice of concept and access to knowledge. As already mentioned, in Mkize's study (2002, p. 51), if bewitchment was suspected there was a delay in seeking help from the public mental health care system. In these cases people applied the "traditional" concept and tried to seek help with a traditional healer or "sangoma". Another study (Mazibuko 1989, p. 101) showed that parents often perceive CP as a form of mental retardation. They try to apply a medical model and due to a lack of understanding develop misconceptions about their children's disability. The treatment was obviously chosen or not chosen in accordance with the interpretation of their child's problem. Interpretations of disability that negatively affected the person's life were often reported. Ntuli (2004) for instance explained that blind children in rural areas of South Africa are often kept hidden inside. People try either to protect them or are ashamed, as they believe that the

blindness is a curse. Their interpretation of disability leads to a logical and rational reaction, in this case exclusion. Literature on the conceptualisation of disease and disability in Zulu-culture is very rare and beside Ngubane's major contribution there is only very little available. Therefore my thesis will attempt to explore the meanings and concepts of disability in greater depth.

The above bodies of literature reflect on the different theories about disease and disability. To place disability in the broader context of HIV/AIDS I will in the following subchapters review the literature on sexual culture, gender and HIV/AIDS.

2.2 SEXUALITY, GENDER AND HIV/AIDS

2.2.1 STUDIES ON HIV/AIDS

HIV/AIDS is a major Socio-economic issue that affects people in South Africa in many different ways. Especially south of the Sahara AIDS became a pandemic not previously known to the world. Social consequences are revealed through family systems being dissolved and restructured and an increase in the number of orphans as well as prostitution and crime as alternative means of making a living (Harrison, Xaba, Kunene, & Ntuli 2001, p. 73). South Africa is one of the most severely affected countries and the province of KwaZulu-Natal (KZN) remains the epicentre of the HIV/AIDS pandemic. Being the epicentre, KZN also seems to attract enough research and has three major research sites, namely: the African Research Centre, the HEARD and the HIVAN organisation at the University of KZN.

Literature on AIDS in Africa represents a vast and ever-expanding area of professional writing. A fair amount of studies on HIV/AIDS in Africa measure the prevalence rate of HIV. Prevalence rates can be quite confusing as almost every study comes to a different result (appendix 5,6,7). The problems seem to lie within the choice of study participants and in mathematical matters. The Nelson Mandela study (2002), which used volunteers and had a sample representative for South Africa in relation to age, income and gender, comes to a prevalence rate of 11,4 % in South Africa and 11,7 % in KwaZulu-Natal. The labour relation council (Rehle & Shisana 2005, p. 6) drew similar results with a prevalence rate of 12.8% in educators

in South Africa. This study was also based on volunteer testing and had a very high respondent rate (97 % consulted Prof. Samuel, UKZN).

The South African Department of Health, with its antenatal testing, arrived with a prevalence rate, in 2002, of 24 % and in 2004 of 29,5 % for the whole of South Africa and 40,7 % for KwaZulu-Natal. Whiteside and Sunter (2000, p. 51) obtained similar results quoting a prevalence rate of 22,4 nationally and 32,5 % for KwaZulu-Natal in 1999. An interesting point is that the authors argue that antenatal clinic data can be considered to be representative of the broader population, if a ratio for female to male infections could be established (Whiteside & Sunter 2000, p. 52). They also did not see much difference between the urban and the rural areas as reported from other African countries. This, they explain, is as a result of a good transport system and South Africa's mobile population, which has enabled the virus to spread throughout the country (2000, p. 53). Analysing the infection rate of adults (15-59 years) for 2001 they calculated a prevalence rate of 26 % for adults and 17 % for the whole population. The prevalence rates would be comparable with the Nelson Mandela study (see appendix 5). Another antenatal study carried out by the African Centre for Health and Population studies in Hlabisa, KwaZulu-Natal, comes to a prevalence rate of 34,6 % of women. The township areas were significantly more affected than the rural areas (Baetzing-Feigenbaum, Herbst, Welz, & Bennish 2004, p. 3). Using GPS[13] the African Centre (Tanser & Le Sueur 2002, p. 42) was able to show that infection rates were much higher in clinics attached to townships and along major national roads (2002, p. 44).

The variety of results seems to be confusing. On the one hand studies based on volunteer testing, which approach a broader part of the population, show medium prevalence rates. They are however often criticised as not being representative. The argument lies within the probability that people who know their positive status or who are afraid of being HIV positive will not volunteer. The result could therefore gloss over the true situation. On the other hand studies that use antenatal data come to very different results and have very high prevalence rates. They are often criticised for not being representative on a national level and that they only show the prevalence rates of sexually active middle class to poor women. Even though the

[13] GPS – Global Positioning System

prevalence rates show very different results, all studies point to a similar scenario. HIV/AIDS seems to be consistently on the rise in South Africa and KwaZulu-Natal is one of the most severely affected provinces. Infection rates are highest in the age group between 15 and 35 years and women seem to be more affected than men.

The overwhelming majority of studies available on AIDS in Africa are largely quantitative studies produced through the use of various research techniques. Widely used is the Rapid Assessment Procedure (RAP) described by Scrimshaw and Hurtado (1987). Studies based on RAP along with studies based on surveys of Knowledge, Attitude and Practice (KAP) bear the dubious distinction, in the anthropological world, of being ´quick and dirty´. Researchers often used these methods in order to quickly gather qualitative information, which in effect is never really qualitative and brings only a limited insight into people's complex experiences with disease. Leclerc-Madlala (1999, p. 37) therefore argues that academic knowledge of AIDS in Africa is still largely "piecemeal knowledge", and limited in terms of depth and quality. She rather suggests the use of participatory research and favoured Participatory Action Research (PAR). This is, in South Africa, an increasingly popular approach as it enhances the principles of social justice like equality, restitution and procedural justice and this then determines the research process. The researcher will try to intervene and empower participants so that they can profit from the research immediately.

Using PAR Muthukrishna (2006) tried to engage her participants in a meaningful exchange, so that the participant would have the opportunity to talk about the AIDS related topics, that they do not usually get the chance to discuss. The study particularly shows the disabling effects of HIV/AIDS. It is argued that the "safe spaces", that participatory research creates, enables the participants to share stories and experiences that were in themselves transformative and emancipatory. This does not however mean that participatory research will guarantee the achievement of those ethical qualities. Francis, Muthukrishna and Ramsuran (2005, p.12) show rather that it is the researcher's attitude and methodological approach that creates these "safe spaces", in which people feel free to talk.

Besides these recent studies there have also been substantial studies on AIDS in Africa, which focus upon the social cultural factors, and their influence on people's behaviour. Caldwell (1996), like many authors, cited cultural forces such as the subordinate position of women in society, including the female economic dependence on men, and a general breakdown of traditional moral and institutional structures that once acted as a constraint to the sexual behaviour of women.

As an anthropologist, Green (1988; 1993) has produced studies on a variety of diseases and has centred his AIDS work mainly around traditional healers. He explored their experiences with and responses to the growing epidemic in Southern Africa. He already argued, in 1994, in favour of a closer collaboration between traditional healers and biomedical practitioners as an important strategy for managing the HIV/AIDS epidemic in Africa.

Taylor (1990) and Preston-Whyte (1996, p. 318) both argued that the cultural framework within which people live needs to be taken into account when designing interventions aimed at influencing sexual decision making. Schoepf (1992, p. 275) therefore presses the point that HIV in Africa doesn't spread as quickly "because of exotic cultural practices but because of many peoples' normal response to situations of everyday life". Understanding the sexual culture is therefore essential to understanding AIDS in Africa.

Gronemeyer, who conducted most of his research in Namibia, presses the point that HIV/AIDS intervention needs to understand the cultural interpretations of disease and sexuality. In the onslaught of HIV/AIDS old imaginations of "being body" rather than the western imagination of "having a body" doesn't allow a person to feel that they are able to look after their own body (Gronemeyer 2002, p. 28). Sexuality and fertility are strongly connected to each other and in the African cosmology death doesn't fit into this constellation. Gronemeyer therefore argues that people first need to change their attitudes towards their own body and sexuality before HIV prevention could be successful.

For South Africans this is an especially hard lesson to be learnt considering that they have only recently won their freedom and the efforts of keeping their own long

marginalized culture alive are now threatened by an invisible enemy. People want to find their African roots and be proud of them. It is therefore a reality that people often may not want to listen to the westernised professional whom they perceive as telling them what to do.

Gronemeyer (2002, p. 18) also argues that the modernisation of the African world and the recent processes of globalisation have created a perfect "climate" for the HIV virus to spread fast. The building of highways and streets that reach out into every little village, the migrant worker systems that keep spouses from each other and encourage multiple partnerships, the destruction of subsistence lifestyle and the development of sex as an income stream are all seen by many authors as responsible for the swift spread of HIV (Gronemeyer 2002, p. 18; Whiteside & Sunter 2000, p. 25). Whiteside and Sunter (2000, p. 60) also argue that the mobile South African society particularly along the main transport arteries offer great scope for concurrent partners and with this a subsequent increase in the risk for HIV infection. Data from the African centre (see above) supports this theory. The two authors (2000, p. 62) also argue that countries with low levels of social cohesion and relatively high incomes face the most rapidly growing epidemic with the highest levels of infection and have categorised South Africa as one such country. The grotesque reality is that whoever persists with risky behaviour and does not accept the biomedical dictature will die. Gronemeyer's conclusion could not be truer than in the case of South Africa. The long denial of the link between HIV and AIDS has unnecessarily mystified AIDS and created uncertainty between South Africans and this is believed to have led to unnecessary infections. In addition to this the gendering effects of the epidemic have been discussed and this shall be reviewed in the following body of literature.

2.2.2 SEXUAL CULTURE AND GENDER STUDIES

From an epidemiological point of view South Africa is known to have a "Pattern II" transmission of HIV, which means heterosexual transmission of HIV and mother to child infections are common. Statistical measurements show a severe infection rate, especially with regard to women, and AIDS related deaths are constantly on the rise. Although most people in South Africa know what AIDS is, there is still a very slow

change of behaviour, as sexual behaviour is determined by economic, social and cultural factors. Various ethnological research has been conducted which tries to understand the inner processes of HIV/AIDS and sexuality. A fair amount of qualitative AIDS research has focused on sexual negotiations and sexual decision-making in Africa. In Southern Africa, researchers have focused on countries like Mozambique, Botswana, South Africa and Zimbabwe.

Exploring sexual behaviour, Machel's (2002) research in South Africa's neighbouring country, Mozambique, found that young women aged 14-20 were engaging in risky sexual behaviour due to socio-economic factors and/or patriarchal beliefs and norms. Similar results were found by Campell (2001), whilst conducting research in South African Townships. Despite the high levels of infection and the fact that people are already aware of HIV/AIDS, levels of perceived vulnerability are low, and unprotected sex is still common within townships.

Analysing the problem from a more quantitative perspective, Buga (1996) interviewed teenagers in the Transkei, the neighbouring district of KwaZulu-Natal. He found that 25% of births are from teenagers, 75% of whom are unmarried. In the secondary schools that he approached, 74.6% of the teenagers were already sexually active. Only 182 (23.5%) of these teens had ever used a modern method of contraception and 241 reported at least one pregnancy. Major reasons cited for initiating coitus included: forced by partner (28.4%), peer pressure (20.0%) carried away by passion (15.1%), to prove normality (11.7%) and to prove love of boyfriend (10.1%). The reasons provided by sexually inexperienced girls for delaying intercourse included: religious values (24.4%), fear of pregnancy (23.8%), wish to wait for marriage (20.0%), fear of AIDS (15.6%), not emotionally ready (8.6%) and fear of STDs (6.4%). Knowledge of reproduction was low, with only 19% able to identify the fertile phase of the menstrual cycle. 64% of the experienced and 73.5% of the inexperienced girls disapproved of premarital sex while still in school; only 27.6% and 11.4%, respectively, supported the inclusion of sex education in the school curriculum (Buga, Amoko, & Ncayiyana 1996). Overall, these findings indicate that early sexual maturity, as well as the early onset of dating, and the poor knowledge of reproductive biology and contraception leads to unprotected sexual activity. Buga suggests a need for school-based family life education and that this should be taught

before girls become sexually active. Findings by other researchers such as Harrison (2001), reflect a very similar picture concerning young girls in KwaZulu-Natal.

In the general literature gender roles and the concept of masculinity are examined (Thorpe 2001, Lewis 2000, Murphy 1998). These results also suggested that safer sexual practices and mutual consent are hindered by several factors. These include: sexual violence and coercion, the negative symbolism of condoms, gender imbalance in sexual decision-making, and peer pressure concerning sexual performance.

Of particular relevance are those studies that have focused on explaining the inner meanings and the ´gendering´ of HIV/AIDS in Africa. One of the first people to approach this was Ingstadt (1990). Conducting her research in Botswana, she discussed how informants often used female sexual anatomy as a point of reference, describing women as “dirty” and potentially more prone to carrying disease than men. Ingstadt therefore argued that such notions could ultimately lead to blaming woman for the spread of AIDS. Leclerc-Madlala (1999) proved with her thesis, conducted in the Marianhill area in KwaZulu-Natal, that the theme of ´dirty´ woman plays a major role in the cultural related interpretation of HIV/AIDS. The belief of “umnyama” or pollution is associated with women and this is linked with HIV/AIDS. Women are seen as “dirty” and “dangerous” and often blamed for spreading HIV (Leclerc - Madlala 1999, p. 42). She even quotes through her research the notion that “Woman is AIDS”, describing women as the source and disseminator of HIV/ AIDS (1999, p. 41).

Wood (Wood & Jewkes 1996) and Leclerc-Madlala (1999, p. 43) describe how violence often forms part of the ´sexual repertoire´ of young men in KwaZulu-Natal. Abdool-Karim and Morar (Abdool-Karim & Morar 1994) as well as Hadden (1997) identified the women’s fear of violence and feelings of powerlessness as a major barrier to safer sex practices. Leclerc-Madlala (1997, p. 371 f.) even describes the phenomenon of young male gangs in the Durban area who raped women with the aim of infecting them as a kind of punishment for their own infection. Similarly Whiteside and Sunter (2000, p. 66) explain the recklessness of young men that know their positive status with an attempt to compensate for not having long to live.

Early studies in the 1990`s (McGarth 1993) already suggested that women accept multiple sexual partners due to economic need and sexual satisfaction. McGrath also showed that women did not even consider using condoms as they felt that their partners would never comply with this. Several other studies have strengthened this point. In KwaZulu-Natal Leclerc-Madlala (1999, p. 40) and Preston-Whyte (1996, p. 321) showed that using condoms is culturally unacceptable as people see this as a sign of not trusting each other. Leclerc-Madlala shows how "condomless sex" is an adaptive practice that helps women to maintain idealised images of relationships and of oneself (1999, p. 32). Condoms are therefore rather used with strangers or prostitutes than with a permanent partner.

Conducting qualitative research Tillotson and Maharaj (2001, p. 94) described how myths interfere with condom acceptance, when men believe that by using the free condoms from the hospital they could get infected with HIV. Men also fear that by using a condom a sangoma could use their sperm for "ubuthakathi", witchcraft and harm them. Dlala (2001, p. 82) also mentions that people refuse to use condoms as they believe that their partner does not want them or that they would reduce sexual satisfaction. Adolescent males in particular believe that they could judge whether their partners were infected or not (Tillotson & Maharaj 2001, p. 92), were prone to experimentation and risk taking (p. 87) and only use condoms with so-called affairs and not with their girlfriends (p. 93). Myths about the origin of AIDS and false information about medical cures are also still confusing people. Tillotson and Maharaj report that some of their participants believed that one could get infected with AIDS by eating oranges (2001, p. 94) and could be cured by sleeping with a virgin (2001, p. 88). The problematic of "virgin cleansing" (Whiteside & Sunter 2000, p. 58) was described by several other authors and will be explained in more detail later.

People in South Africa also engage in sexual relationships from a very early age and accept multiple partnerships. Often fear, coercion and peer pressure mixed with poor guidance by the older generation leads young people to take risks (Tillotson & Maharaj 2001, p. 88). Myths about the necessity of early sex also lead youngsters into early engagements with sex. Harrison (2001, p. 75) describes the fear of young boys that evil spirits could harm then, if they did not have sex close to puberty. In his work one also finds the misconception that possible pain or problems concerning

impotence, would arise if they did not start sex early. Some even believed that they would be more likely to impregnate a girl, as they would have more sperm. These misconceptions can possibly be explained with Tillotson's and Maharaj's findings that young males often lacked basic knowledge of the human body and its functions (2001, p. 88). In comparison to Buga's study in 1996 this suggests that in recent years there has been little improvement in educating people about the human body, while on the other side knowledge about HIV/AIDS has been spread without affecting or changing behaviour.

Women on the other hand were found to hardly consider feelings of love when choosing a partner (Dladla, Hiner, Qwana, & Lurie 2001, p. 80). In addition they were described as either looking for sexual satisfaction outside their marriage or for an extra income or source of material goods.

The consequences of Apartheid led to spouses being separated for months at a time, and this encouraged multi-sex relationships. Nevertheless Preston-Whyte concludes that the "answer condom" may not be suitable for every cultural reality (1996, p. 318). This comment was now made over 10 years ago and an alternative seems not to have been found. The so often proclaimed abstinence does not seem to be a local solution either as this does not conform to the realities of African life. This leaves Africa in a dilemma and those who do not "condomise" will die. People are only just starting to grasp this concept, while traditional leaders still proclaim, "using condoms is fooling oneself" (Ziba Jiyane, Sunday Tribune 14. Aug 2005). The government only recently stopped denying the connection between HIV/AIDS and sexual violence is still a reality for many African youngsters particular females (Leclerc - Madlala 1999, p. 133).

AIDS and sexuality is still described as a taboo topic (Dube 2004) and this is only changing at a very slow rate. Research indicates that many youngsters find it difficult to get appropriate advice and guidance. For people with disability this is even more difficult. Reflecting this Dube, himself disabled, reported during a symposium on HIV/AIDS and disability in 2004, that people with disability in South Africa are often victims of abuse and at the same time they are not regarded as a proper sexual partner and therefore not in need of sexual education (Dube 2004).

In her study of people with paralysis from spinal injuries, Seymour (1998) explores the cultural influence on sexuality. She analyses that in sexual terms “ideas of normality and abnormality are tied to the rigid parameters of male-female dichotomy” (p. 153). Because of this people with disability have to challenge more than one social category. They have to fight against the perception that they are asexual as well as for the recognition as a woman and a man that will be acknowledged not only as a social being and a contributing individual but also will be accepted as a sexual partner. Comparing the effect of spinal injuries on the sexual functioning of women and men Seymour concludes that women experience much less practical sexual dysfunction than men (1998, p. 130). Society, however, does influence the ideas, values, bodily manifestations and social practice associated with sexuality and therefore the “physical advantage” women with disability face is only an “empty blessing” in terms of the reproductive opportunities. Their male counterparts, even though physically more affected by their injuries, experience less rejection as sexual partners (Seymour 1998, p. 132). Men and women are attributed roles, with women being the care givers and men traditionally being the providers. This influences sexuality to such a degree that a woman will be more likely to care and love a paralysed man than the other way around. Another important point mentioned in Seymour’s study is the influence of parents on their offspring’s sexual development. Often overprotected and dependent on their parents, young women with disability, particularly, find it difficult to enjoy privacy, gain independence and discuss sexual matters as parents might deny their offspring’s sexual development (Seymour 1998, p. 133). How this is discussed in relation to HIV/AIDS shall be reviewed in the final body of literature.

2.2.3 STUDIES THAT COMBINE DISABILITY AND HIV/AIDS

At the turn of this millennium it was commonly assumed that individuals with disabilities were not at a high risk of HIV infection. It was incorrectly believed that they would be sexually inactive, unlikely to use drugs or alcohol, and less at risk of violence or rape than their non-disabled peers (World Bank 2003, p. 3). Despite these assumptions disabled people perceived themselves to be at higher risk of HIV infection due to disability regardless of their awareness levels (report Disabled People International 26.12.2004; AIDS Action issue 35 December 1996).

The World Bank's Global Survey on HIV/AIDS and Disability (Groce 2004) was the first research conducted that brought the fields of HIV/AIDS and disability together. A pre-survey cited the lack of data on disabled populations and HIV throughout the Developing World. A survey conducted in Uganda and Rwanda then showed that adolescents with disabilities are actually highly vulnerable to HIV and sexually transmitted infections due to sexual abuse and misconceptions about sexuality and rights (Yousafzai & Edwards, Global survey 2004). Issues of effective control in relationships and sexual decision-making were also raised as a problem. Linked to the same survey was research about the deaf population in Swaziland (Groce, Yousafzai, Dlamini, & Wirz 2005) and Nigeria (Groce, Yousafzai, & Van Der Maas 2005). Both studies could identify significant differences in levels of knowledge about HIV/AIDS between the deaf and the hearing population. While prevention methods like condom use and abstinence are well know among the deaf population other misconceptions are still widespread among deaf people in general (Groce, Yousafzai, Dlamini, & Wirz 2005, p. 8). For instance people with loss of hearing were found to be more likely to believe that HIV/AIDS can be prevented through hand washing and eating healthy food as well as avoiding hugging, kissing, dirty places and sharing of utensils. They were however less likely to know about infection caused through the use of un-sterilised needles (although not in Nigeria), razors and contaminated blood. In both surveys the discrepancy was explained by the lack of access to health outreach efforts and health facilities because sign language is rarely used by AIDS outreach workers or nurses in the clinics. While the global survey concentrated more on the quantitative measurable data and knowledge of HIV/AIDS it did not state whether more accurate information would change the behaviour of disabled people, expose them to less abuse and decrease the risk of HIV infections. It also does not take cultural grown concepts into consideration and therefore cannot fully explain the cultural influence on the fast spread of HIV and its effect on disabled people.

As the Global survey never included South Africa, there is no data about people with disabilities that can be made accessible in this country. Emily Ntuli and Andrew Dube from Disabled People South Africa (DPSA) however reported similar challenges for disabled people in South Africa (Ntuli & Dube Symposia Dec. 2004) as found by the global survey in other countries. They explained that their people did not have the

same access to information due to the lack of disability appropriate material, the assumption of caregivers that they do not need information, less peer education and isolation. Also the access to health services and VTC (Voluntary Testing and Counselling) was problematic because of the long distances to local clinics, the lack of confidentiality and the attitudes of the health workers (Ntuli 2004). Andrew Dube (2004) explained at the same symposia that people with disabilities can not always rely on the commonly used contraceptives (Gräber, Hanass-Hancock, Müller, Wall, & Zimmerman 2008). In the case of a physical disability they might not be able to physically use condoms. This applies to both males and females. In other cases medication might interfere with contraceptives. Both representatives made it very clear that HIV/AIDS is a very real problem for people with disability in South Africa and that their needs in this regard are highly neglected by their society. It also became clear that people in areas like KwaZulu-Natal, with a large population of indigenous people, have a different interpretation of disability and that one has to understand these concepts in order to understand the vulnerability of people with disability.

People's approach and attitude towards disabled people is influenced by their concept about disability. Disability is therefore a cultural construction and its interpretation can have a positive or negative effect on the person. This also affects a person's ability to protect him/herself from HIV infection. How disability and HIV are conceptualised is the focus of this thesis and the links between the two will be discussed in the following chapters.

3 RESEARCH DESIGN AND METHODOLOGY

3.1 APPROACH TO THE STUDY

3.1.1 RESEARCH APPROACH

This study was designed to provide empirical data on the concepts of disability, cultural values concerning disability and its Social Representations in KwaZulu-Natal. The study also attempts to analyse the various stigmata associated with various disabilities and how this influences the way people interact with each other and increases exposure to the risk of HIV infection. To approach this matter I was particularly interested in people's individual experience of disability. Experience is an overused term in social science and therefore I want to clarify my view at this point. In accordance to Kleinman and Seeman (2000, p. 234) I understand experience as a representation of "the intersubjective felt flow of events, bodily processes, and life trajectory which always takes place within a social setting." On the one hand experience is an outcome of cultural categories and social structures that interact with psycho-physiological processes in such a way that a personal social reality is constructed. Social reality on the other hand is a product of meaningful social interaction as perceived from perspectives of those involved, and not from the perspective of the observer (Kleinman & Kleinman 1991, p. 277). I aimed to capture these individual experiences of disability and the social reality of the phenomenon. Exploring these two aspects I had to inquire deeply into people's notions and interpretation of disability. Due to the fact that I had not entered the field with any sort of preformed hypothesis, more inductive and explorative ways of research seemed necessary while approaching my topic. Such an inductive approach allowed me to generate concepts in the course of my research (David & Sutton 2004, p. 79). Quantitative ways of collecting data, which are usually more deductive, therefore seemed unsuitable while approaching the topic. On the contrary, qualitative methods such as observation, interviewing, drawings and ranking exercises, were able to access the individual experiences and Subjective Theories and with this the Social Representations of disability and seemed therefore to be the better choice for my study.

As a researcher I tried to be sensitive to the priorities and notions held by those whom I approached. A useful qualitative approach for this purpose was ethnography. Ethnography literally means ´writing about people´. It sees people as experts in the field of what the researcher wants to find out about, rather than as objects (Burns 2000, p. 393). Ethnography initially involved descriptive data collection as the basis of interpretation and has often been used while studying sick-role behaviour. Using this approach I hoped to create a dynamic picture of the subjective life experiences of people with disability and in this way capture the social reality of these people. I am however aware of the fact that meanings and interpretations are not fixed entities and that they are generated through social interaction and can change over time. I also aimed to capture these dynamics within my study.

Using an ethnographic approach meant that I had to study people's behaviour towards disability in an everyday context. I had to base my research on analysing people's conversations and reflections about their life. To accommodate people I had to use a less structured research design and keep myself open and flexible with my choice of participants and where and how I would conduct interviews. It also meant approaching only a small number of people and collecting more descriptive data (Hammersley 1998).

As is often done in qualitative research, I would select particular cases or certain bounded realities and study these in depth. In my study these cases or realities were related to disability. Using an interpretive paradigm, it enabled me to investigate the subjective experiences of the participants. Through this I hoped to gather a greater understanding of the broader phenomenon than would have been otherwise possible. The focus of my research was to understand Subjective Theories of and the reaction to disability and how this links to HIV/AIDS. In accordance with the tradition of the Symbolical Interaction theory (Blumer 1938) I therefore based my research on the symbolic character of social actions. Research with such an approach concentrates on the way in which the participants perceive and reflect others (Flick, Kardorff, Keupp, Rosenstiel, & Wolff 1995, p. 29). It also takes into consideration the experiences people have had in their lives and how they relate meaning to this, therefore the reconstruction of Subjective Theories became the instrument for my research of the world of people with disabilities.

At the time of my study it was very popular in AIDS related research to use a participatory action approach, where the participants can immediately profit from the research and are included fully in the research process as equal partners. Often these types of studies are done by a research team and have some financial backup (Preston-Whyte 1996). I usually approached my participants as an individual and therefore did not feel confident to use this method on my own. I did however include participatory elements into my study. I included DPSA and DICAG[14] into the process of choosing valuable participants. They also influenced the design of my research questions and were included in feedback discussions through focus groups at the end of my research. It is also possible that the various interviews and visits might have had a positive and empowering effect on my participants, as I was often able to give advice and comfort in the aftermath of the interview. I can however only speculate about this.

3.1.2 RESEARCH CONTEXT

KwaZulu-Natal (KZN) is one of 9 provinces in South Africa. It is situated in the south east of the country. I chose this province as the research site for my study as it is one of the epicentres of the HIV-pandemic. I have also spent many years volunteering and visiting KwaZulu-Natal and know the area well. Within KZN I focused on the Durban metropolitan area which is commonly known as eThekweni. Data from other municipalities has also been collected so as to get a broader picture.

The broader context of KwaZulu-Natal will be described in chapter 4. Here I only want to raise the point, that the process of collecting data has been influenced by the KwaZulu-Natal economic situation as well as its cultural and historical heritage. The issues that are of particular importance in this context are:

- the high rate of unemployment and poverty in the province,
- the historical theme of political and social violence,
- stigmatism and the culture of silence related to HIV/AIDS,
- language and race barriers between people.

[14] DPSA – Disabled People South Africa, DICAG – Disabled Children Action Group

These four points are not only typical for KZN but also for the broader South African context. Important to know is that these factors have influenced the way I was able to collect my data. For instance it was not possible for me, particularly not, as a European, to walk into any township and see ´what it is like´ as there would have been serious safety concerns. Such areas I had to approach through my gatekeepers and their local affiliates.

The above mentioned points have also influenced the sampling. It was, for instance, relatively easy to identify veterans from the struggle, who became disabled through their involvement in the struggle against apartheid. These people are very often well integrated within the local and national disability organisations and therefore easily approachable. As I was not interested in their story alone, I had to make a particular effort to also meet people of ´ordinary descent´. In the course of my research this became easier as I could approach people through local branches of disability organisations.

In general, people were very open and it was not difficult to find participants for my research. One reason for this might have been the fact that people with disabilities are in general of little interest to the public and therefore have not yet been over researched. They seemed to have experienced the interviews rather as welcome highlights and they added interest to their lives. Generally speaking there was only one group of people who were difficult to approach: People who had a disability and were HIV positive were difficult to identify and seldom agreed to be interviewed. Some participants argued that the double stigmatisation made it impossible for disabled people with HIV to come out. The same problem caused difficulties for my initial interview partners (gatekeepers) to provide me with contact details. As people got to know me, relatives, caregivers and sometimes people with disability themselves did however volunteer to discuss these issues. This took some convincing and patience on my part, but did provide me with some original data of people with disability and HIV. I sometimes had difficulties visiting people in their homes or in their communities as the current levels of violence made me vulnerable to crime. I therefore always had to link myself to other projects so as to safely access areas I was not familiar with. My sample is therefore influenced by these doctrines. By approaching people with disability through their local disability organisation or

locally based research projects, I found that quite a number of my participants spoke English well enough to be interviewed in this language. I did however use certain Zulu words, as the meanings would otherwise have got distorted. A few interviews, particularly those ones which were based in rural areas, were conducted in Zulu. For these interviews I used a translator to facilitate the interviews. The presence of a third person might have influenced the outcome of the interviews. The translator that I used was well qualified and had experience in facilitating research on disability as well as on HIV/AIDS. The interviews were therefore conducted to the highest standard possible.

Usually I had very few problems in approaching people for interviews. At the beginning of my research I expected to encounter sceptics as I was just another white European trying to write about African people, their custom, culture and problems. I however encountered very little resistance and was usually met with interest. In some cases the fact that I was a European seemed to be an advantage rather than a disadvantage as people did not feel threatened or under any cultural restraints when talking to me. One participant who disclosed his HIV status to me (I was the second person he had told about it) explained this in the following way: As I was from a foreign country and not associated to his culture or village I would disappear in much the same way that I had appeared that afternoon on his doorstep. He was convinced that I would not talk about his status nor would I have any chance to do so as I was not “black” nor did I belong to his community.

3.2 STUDY SAMPLE

3.2.1 STRUCTURE OF THE RESEARCH PROJECT

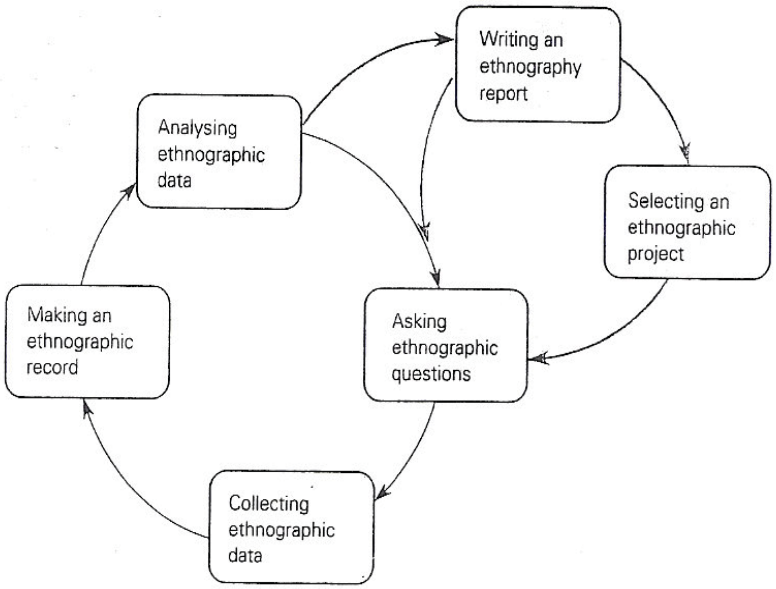
In ethnography the researcher needs to recognise the fundamental need to go where the participants spend their time. The quality of my study therefore depended to a large extent on the group’s acceptance of me as the researcher. Gaining entry into a group is usually best accomplished through a mutual contact that might either become or can recommend a person that can operate as a ´gatekeeper´ to the study field (David & Sutton 2004, p. 107).

During my research in KZN I received support from DPSA[15] and DICAG[16], who I tried to include into my research as much as possible and whose regional managers operated as my gatekeepers. The research unit HEARD[17] at the University of KZN also provided me with support. All three stakeholders invited me to team meetings and workshops; they helped me to find possible interview partners and provided me with professional feedback at various stages of my research. Supported by these three organisations I went through the following steps in the research process:

(1) Contact with DPSA, DICAG and HEARD.
(2) Development of the questionnaire and question guide.
(3) Pilot study.
(4) Improving the research instruments.
(5) Data collection with in-depth interviews.
(6) Transcription.
(7) Coding, categorising and summarising of the individual interviews.
(8) First discussion of interim results with DPSA.
(9) Further Interviews.
(10) Further analysing of interviews and theory development.
(11) Focused group discussion with DPSA
(12) Final conclusions.

Another major task was the actual collection of ethnographic data. Following Burns (2000, p. 400) ethnographic research cycle (see feature 3.1) I started by making broad descriptive interviews (pilot study). This was to help me to gain an overview of the social situation and what is generally of importance for people with disabilities. Then after recording and analysing the initial data I narrowed down my questions and made more focused inquiries.

[15] DPSA- Disabled People South Africa
[16] DICAG - Disabled Children Action Group
[17] HEARD - Health Economics and HIV/AIDS Research Division



Feature 3-1 Ethnographic cycle (Burns 2000, p. 400)

The first step of the analytical work was done after having completed the pilot study. I conducted this study to test my research instrument but also to collect the first set of data and information from my ´gatekeepers´ whom I could use as my prospective interview candidates. The ongoing analysis of the interviews[18] and field observations included a process of discovering further questions. Even so I came into the field with specific questions; through analysing my data I was able to discover new questions that would help to describe the phenomenon of disability in KZN. In the final interpretation and writing process I tried to draw conclusions as objectively as possible. As Burns describes qualitative researchers are generally concerned with the effects that their "own subjectivity may have had on the data they produce" (Burns 2000, p. 414). He therefore suggests to use triangulation and critique by colleagues as an additional check on bias (Burns 2000, pp. 390, 415). Both methods I have used to a limited extent. I am however aware of the fact that my own subjectivity will have influenced the collection, analysis and interpretation of my data. The reader should therefore see the entire conclusion in this thesis as my personal interpretation.

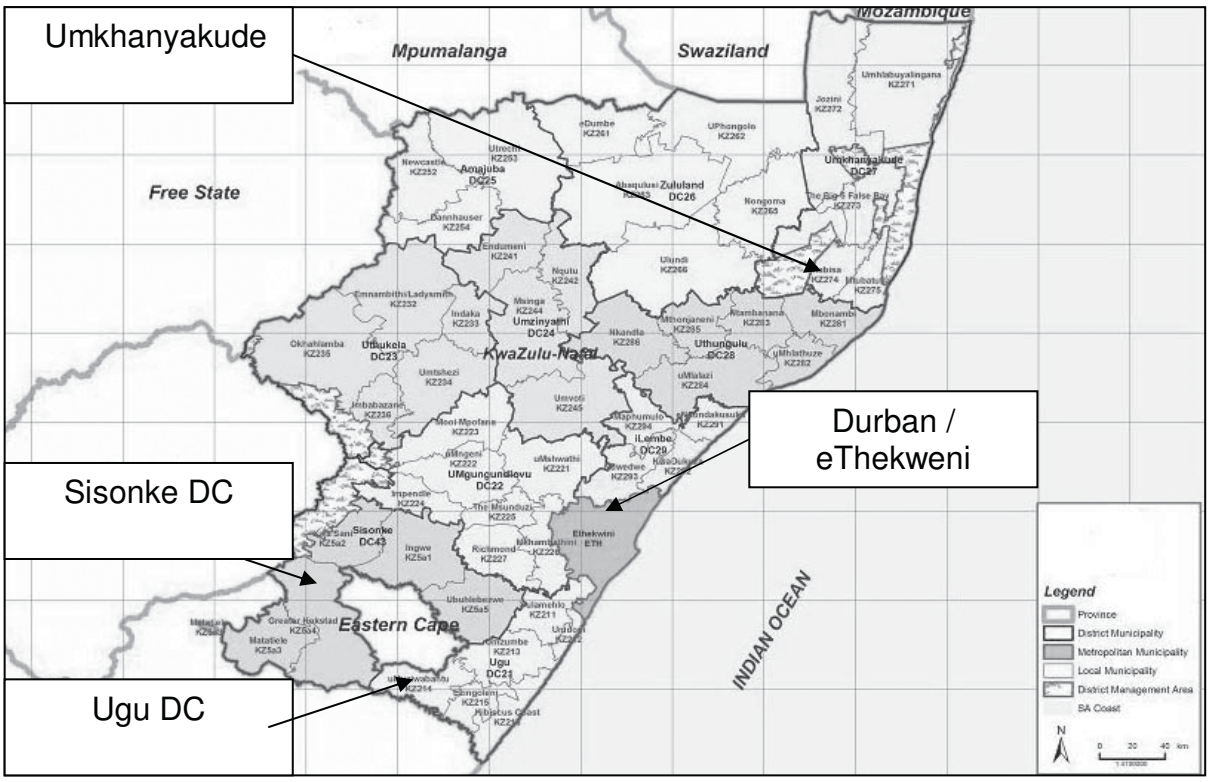
[18] Methodology is described further down.

3.2.2 PROFILE OF THE PARTICIPANTS

Data was mainly collected from three different sources: There were documents and policies, key interviews and focus groups. The selection of interview partners was based on two main criteria: The interview candidates had to either be disabled themselves, or work/live with disabled people. The participants that I chose for the in-depth interviews then became my key informants. Key informants are defined as those people "who, by virtue of the nature of their position and knowledge, can capture and reveal relevant cultural phenomena, especially on disability" (Room, Rehm, Trotter, Paglia, & Üstün 2001, p. 249).

In my study these key informants were predominately people with disability themselves, their parents or their caregivers and professional staff in schools or hospitals. Even though the setting had already been quite specific it was still necessary to select participants. These key informants were chosen through theoretical sampling and snowball sampling. Through snowball sampling, a person, who is identified as a valid member of a specified group is asked to provide names of other people who fit the requirements (David & Sutton 2004, p. 107). I used this approach as I did not always have sufficient potential interview partners. The selection of the recommended interview partners was however based on the method of theoretical and convenient sampling. Using this method I tried to find interview partners who could answer emerging or unanswered questions.

Even though I concentrated my study predominantly on the Durban or eThekweni area I also visited other KZN municipalities. In the map below one can see the areas I approached (feature 3.2).



Feature 3-2 Study sites in KwaZulu-Natal

Therefore people with different disabilities and from different municipalities were approached. As a result I have spoken to quite a variety of people (see table 3.1).

Interview number	Details	Area
1	Woman with hemiplegia and in wheelchair, provincial manager of DPSA	eThekweni (urban)
2	Mother of a child with severe learning disabilities, CBR[19] consultant	eThekweni (urban)
3	Mother of child with severe learning and physical disabilities, manager of DICAG	eThekweni (urban)
4	Man with spinal injury, in wheelchair, paralysed through gunshot	eThekweni (urban)
5	Mother of child with severe learning difficulties, manager of day-care centre in Claremont	eThekweni (urban)

[19] CBR – Community Based Rehabilitation, which provides care and information for people at grassroots levels

6	Visually impaired man, teacher at High School	eThekweni (urban/rural)
7	Business man, visually impaired	eThekweni (urban/rural)
8	Deaf woman	Ugu DC (urban)
9	Man with spinal injuries, in wheelchair, CBR consultant	Sisonke DC (rural)
10	Woman, teacher at Claremont day care centre	eThekweni (urban)
11	Woman, teacher for children with learning disabilities at High School	eThekweni (urban)
12	Mother of child with severe learning disabilities, Claremont	eThekweni (urban)
13	Man, occupational therapist of Murchison Hospital	Ugu DC (rural)
14	HIV positive woman	Ugu DC (urban/rural)
15	Nurse in Claremont clinic, sexual educator	eThekweni (urban)
16	Man with albino condition	eThekweni (urban)
17	Man with cerebral palsy	Umkhanyakude (rural)
18	Man with loss of hearing and AIDS	Umkhanyakude (rural)
19	AIDS patient care giver (for no 18), woman	Umkhanyakude (rural)
20	Man, traditional healer	eThekweni (urban/rural)
21	Girl with albino condition, who visits a school for children with disabilities	eThekweni (urban)
22	Priest and caregiver	eThekweni (urban)

23	Woman, traditional healer	eThekweni/Empangeni (urban/rural)
24	Woman with slight cerebral palsy, who was victim of sexual abuse from a young age	eThekweni (urban)
25	Man with leg amputation who was also HIV positive	eThekweni/Bothas Hill (urban/rural)

Table 3-1 Profile of participants

The main part of my research was conducted while participating in people's lives. I visited people in their homes, during workshops and in projects they were involved in. This gave me a good inside into their living, working and schooling reality and also enabled me to create a personal and comfortable atmosphere for my interview partners. I also collected data through participating in these workshops or in the daily running of a clinic or day care centre. I often had to take down the information from these institutions as memory protocols, as much insight was given to me through informal meetings, break discussions or presentations that could not be taped as these had not been planned.

3.3 METHODOLOGY

3.3.1 METHOD FOR DATA COLLECTION

General approach

Predominantly using interviews for data collection I had the choice to use unstructured, semi-structured or structured interviews. I decided against structured interviewing, as this type of interviewing allows very little or no flexibility. Approaching so many different people I expected to need a highly flexible instrument. Structured interviews would also have provided me with little scope to find out the notions, feelings or perceptions of the respondents that might not fit into the pre-ordained response categories. This was however necessary when I entered a field with little or no previous research available. In addition to this I was also worried that the detachment and impersonal approach of structured interviews would prevent trust

and rapport building between me and the participants. As part of my interviews inquired into highly personal and confidential information (e.g. rape and HIV status) I needed an instrument that would allow me to build a comfortable relationship with the respondent.

Semi-structured interviews allowed me more flexibility while conducting the interviews. Even though I developed an interview guide I only used it as an instrument to remind me of the relevant information, which I wanted to find out about. The questions of my guide were not necessarily used with its fixed wording or order but rather used to give the interview the required direction, so that the content focuses on the crucial issues of my study. This approach gave me the following methodological and ethical advantages:

- the informant's perspective was provided rather than imposing my perspective,
- the informant used language natural to them rather than trying to understand and fit into the concept of the study,
- the informant had equal status to me the researcher rather than being a guinea pig (Burns 2000, p. 425)

A typical semi-structured interview is the In-depth-interview. I used this type of interview to obtain detailed information about life experiences and individual interpretations of disability. I designed these interviews methodically like problem focused interviews described by Witzel (1982) and Flick (1995, p. 105). With these interview techniques, questions are raised and formulated so as to focus on a specific problem. As a technique to explore specific issues I used "Funnelling". With this approach I had gradually to guide the direction of the interview through beginning the interview with a set of broad questions followed by progressively asking more specific questions.

During my research I used the elements as described by Witzel (1982), such as qualitative interview group discussions and analysed the interviews case by case. The fourth element that Witzel suggested, the biographical approach, I only used to a small extent and focused more on certain key points in the life of my participants. I

also used the instruments suggested by Witzel (1982), a short questionnaire, a question guide, transcription and a postscript. In this approach the questionnaire was used to collect statistical relevant data like gender, level of education, occupation, type of disability and so on. Witzel used the questionnaire to prompt the participant in case the interview lost its focus or the participant stopped talking. I very seldom used it in this way. The questionnaire was predominantly used to gather crucial "hard data".

As Witzel suggested, I used one central entry question for the interviews. Crucial communicative strategies that I used while conducting the interviews were prompting, mirroring, encouragement and Ad-hoc-questions (Witzel 1982). I prompted with questions like: "What happened there in particular?", "Can you explain that in more detail?" or "Could you give me an example?"

As mentioned before, participants were identified through theoretical and snowball sampling (Burns 2000, p. 465). Once I decided what kind of person I would like to interview next, I tried to find somebody through my already established contacts (gatekeepers) and took the person most accessible to me.

The Pilot Study

For the pilot study I developed a questionnaire and an interview guide. The questionnaire helped me to gather statistically relevant data. For the question guide I identified three main areas that would help me to inquire into people's understanding of disability and assess HIV-risk factors for people with disabilities. These areas were later used to analyse the data. Questions were formulated for each of the following areas.

- Cultural interpretation and reaction to disability
- Living conditions of people with disabilities
- Sexual culture and HIV/AIDS

Although some of the questions in the pilot study were formulated too academically, four of the participants were able to answer them as they had better educational

backgrounds. The question guide did not always give the participants the opportunity to explain things in the order that they preferred. The instrument therefore proved that it was not flexible enough. In addition to this, one respondent even needed help with some questions, as they were too complicated or not specific enough. I therefore realised that I had to adapt my instrument so as to better facilitate further research.

In the initial pilot study I therefore sometimes diverted from the interview questions for a while and allowed the participant to speak about his/her feelings. The fact that I was investigating their personal situation and wanted to know more about their own subjective interpretation of their lives gave me the latitude to make this diversion. The interviews therefore took a long time and I got much additional information that I did not necessarily need for my study.

The final research instrument

As a consequence of the pilot study I was able to improve on some of the questions in the final question guide. I added an additional instrument that could help me to focus the interviews on what I regarded as the more relevant facts. For this purpose I developed a ranking exercise that I would add to my “entry question”. With this I hoped to give my interview partners an open approach towards the interview and at the same time focus on my research question as well as identify the areas that most mattered to the respondents.

The ranking exercise can be seen as a stimulating item that is given to the participant at the beginning of the interview and is similar to the technique used in focused interviews (Merton & Kendall 1946/79 and Flick 1995, p. 94). Adding this instrument to my research created a “between methods” triangulation (Denzin 1989, p. 237f.). Although the ranking exercise (stimulus) was used more as a didactical instrument to help focus the participant’s attention on the relevant information, it later proved to be useful in reconfirming some of the research results.

Based on this ranking exercise I would start the interview in one of the three main areas of my question guide (mentioned above). Often it was not necessary to prompt my interview partners after the ranking, because they automatically expressed their

thoughts. At the same time I was able quickly to gather the relevant data, as participants kept focused on my topic through the ranking items. A similar method was used by Muthukrishna (2006) while conducting research on children with disabilities, who were affected by HIV/AIDS. The items that I used in this ranking exercise were identified through my pilot study. Through a process of reduction I went on to choose 10 main clusters that would equally represent the three main areas of my research.

The 10 main clusters or key themes were developed out of a list of 30 themes that had emerged in the pilot study. In reading and re-reading data, these common clusters of issues emerged. Some of the themes overlapped and could be united under one cluster. At the end of my analysis I came up with 10 clusters that had a culturally relevant meaning and could be used for the ranking exercise in the main study.

Clusters identified through reduction:

- Beliefs and myths about disabilities
- Attitudes and respect
- Access to transport, education, health service and housing
- Employment
- Poverty
- Protection and security
- Sexuality and abuse
- Relationships and marriage
- Independence and decision making
- Honesty and truthfulness

Once these key themes or clusters had been identified I took each theme and identified or reformulated specific questions that allowed me to probe that theme in more detail. These questions were then used as a basis for formulating my question guide. In the course of the interview I preferred to keep this question guide as an aide-mémoire (David & Sutton 2004, p. 87). In this way the question guide would not dictate the order of questions but it would rather be an instrument to which I could return during the course of the interview. In this way I had a basic orientation of what

I wanted to find out about and at the same time I did not restrict the flow of words from the respondents. Questions had only to be used when a participant did not respond to all key themes as they were presented in the ranking exercise.

For all of the interviews following the pilot study I used the questionnaire, the ranking exercise, the question guide and the postscript as my research instruments. An interview session was usually conducted in the following way: While I was arranging the technical equipment for the interview the participant was filling in the questionnaire. Most participants were literate. I helped filling in the questionnaire in only a few cases. Afterwards I once again explained to the participant what the purpose of the interview was and that all information was going to be treated as confidential. At this point some participants chose to ask me more details about my research. After the formal agreement to start the interview I presented all 10 clusters/key themes on cards to the participants and asked them to arrange them in descending order from the most to the least problematic. Often participants immediately started to explain why they arranged them in the way they did. This made the interview situation very comfortable. In this way each interview started in a different section of my question guide and it was sometimes not necessary to use the questions from the guide at all. On the other hand I was able to use these questions to access more specific information where necessary. The flexibility of the semi-structured interview provided, in this way, more opportunity for the respondent to discuss what he/she meant (Burns 2000, p. 390), and this may well have strengthened the validity of the data. Even though the ranking exercise guided people's thoughts the relatively open question at the beginning of my interviews allowed the participants to express their thoughts in a, for them, comfortable manner. In this way they have expressed their experience of disability in an unrestricted way, which then allowed me to explore their Subjective Theories. Consistently referring to my interview guide enabled me to keep focused on my critical questions. The ranking exercise also made it easy for the participant to come back to these issues.

All but two of the interviews were recorded and later transcribed. The other two had to be written down during the interview, as one participant was not comfortable with being taped, while the other participant being a traditional healer had no electricity available in his shop. Rejections of being taped are explained by the Zulu shaman

Mutwa with the notion that the recording device could capture parts of a person's soul (Mutwa 2003, p. 21). As the participant was still very entrenched in tradition it is conceivable that this was his reasoning behind not wanting to be taped. He did not however explain himself and I did not press the point. Another reason for his reluctance could be the fear of getting into trouble for giving advice about HIV. This is especially likely as the participant was a physiotherapist and maybe not sure how much information he was allowed to give me.

In addition to this, one focus group interview was used to reconfirm and discuss research results with stakeholders. In this interview I presented, to a small group of people with disabilities,[20] my final results. I also presented various charts and tried to reconfirm if the participants could identify with my interpretation or if some basic misunderstandings had to be rectified. The purpose of this group was also to use the interaction between the participants to generate discussion about the topic. I hoped that the discussions would be more detailed and wider ranging than the one-to-one interviews. From an ethical perspective this group interview also gave the participants the opportunity to criticise my work and thus have more control over the research outcome. The group I used was small and consisted of 5 people. As a stimulus for discussion I used diagrams that I had developed on disability, quotations and results from the ranking exercise. In a twenty minute presentation I outlined the basic concepts of each section of my research and asked the participants for improvements or rectifications. I had a small aide-mémoire prepared to guide me through the process and to keep the participants focused on my topic.

3.3.2 DATA ANALYSIS

During my analysis I tried to convert the concrete realities that I had found in the field into a conceptual understanding of the phenomenon of disability and bring this into relation to HIV/AIDS. During the construction of my theory I used analysis based on grounded theory approach as my main tool. This type of analysis is used to identify themes, concepts and meaning. It is a form of classifying content (Burns 2000, p. 432). The greatest strength of this analysis is that it can be conducted after the interview, so that the initial setting is not disturbed. The coding is also determined

[20] Here I used stakeholders form DPSA and DICAG that I had already interviewed.

after the event. In addition to that it was possible with this approach to choose initial categories in the coding process that were generated by the respondents and their perception of their environment. For the interpretation of especially rich or contradicting data I used discourse analysis. Discourse analysis is used for a wide range of topics, from semiotics to narratives (David & Sutton 2004, p. 197). All of them have in common the resistance to a mechanistic reduction and application of research and are therefore descriptive case studies. I have used these case studies while trying to understand reaction chains, particularly how the interpretation of disability led to HIV exposure. Even though for the main part of my research I used the grounded theory approach, which means that I was counting and interpreting certain patterns that emerged in the data, I used discourse analysis to explore certain cases in more depth. Questions that answered the how and why certain individuals were exposed to certain situations was of interest at this stage (David & Sutton 2004, pp. 49, 197).

Starting with a set of data (transcribed interviews) I read through the material and tried to identify units of meaning that would give me information about one of my three study areas (1. Concepts of disability, 2. Living conditions of people with disabilities, 3. Sexual culture and HIV/AIDS). Using open coding (Flick 2002, p.259; Strauss 1994, p. 57ff) I identified common themes and coded them as I worked through the data. These codes were initially text based, so meaning was not distorted at this point. At this stage codes could therefore refer to a phrase, sentence, or the idea of a paragraph, as used and described by the interview partners.

The main part of my coding was supported by the computer software programme known as MAXqda. In the next step I tried to find codes with meanings that would describe the same phenomenon and therefore fit into one category (axial coding, Flick 1995, p. 201; Strauss 1994, p. 63). The ensuing categories were once again named, using the data as a guide to decide what a category should be called. My knowledge about theories of disability and disease seeped into the process at this point. Rereading the data I tried to find common themes for all three study areas (Strauss 1994, p. 63). At this point I began to particularly examine the extent to which participants share a common theme or issue and where they were contradicting each

other. At the end of my analysis I had reduced my material to five main themes each with its own categories.

Theme 1: Living conditions of disabled people in KZN

- Access problems
- Gender imbalances
- Influence of the support system

Theme 2: Concepts of disability

- Concept of supernatural causes
- Concept of natural causes
- Concept of increased vulnerability
- Social concept of disability

Theme 3: Sexual culture and HIV in KZN

- Gender relations are driven by the concept of respect and superiority
- Sex is still a taboo topic
- Sex is often seen as a type of income

Theme 4: Disability as an intervening condition

- Sexual behaviour of disabled people is often seen as abnormal
- Sexual contact with disabled people is often seen as an adventure or an easy unprotected source to fulfil sexual desire
- High exposure to HIV/AIDS risk through sexual abuse and violence
- Myths about disabled people increase the risk for sexual abuse

Theme 5: Coping strategies

- There is a tendency to forbid or try to delay sexual contact for people with disabilities
- Self responsibility and sexual education as a strategy
- Ignorance and denial may increase the risk for HIV infection

Thereafter I studied these issues and themes in order to interpret information and make assertions about my findings. The 5 main themes that I identified influenced the structure of this thesis tremendously and drew the outline for the following

chapters. During the process of interpretation I adopted the “think display” approach into my analysis. Davis and Sutton suggest (2004, p. 194) that this approach should be used beyond the representation of final research outcomes and should also be used in the act of analysis. They go on to explain that by “means of visual reduction the complexity of qualitative data can render comprehensible in rather the same way that quantitative data is rendered comprehensible by means of tables, graphs and statistical procedures” (as above). Davis and Sutton recommend matrix displays (grids) and network diagrams (flow and links) as the most useful representational devices, of which I predominantly used flow charts and diagrams. The end results have been recorded in this thesis and are aimed at describing and simplifying single cases as well as enabling comparison between cases.

As a final analytical step I tried to identify the interrelations between the main themes and drew “reaction chains” that would help to answer my research questions. Here I explored, in particular, the connection between Social Representations and Subjective Theories on disability and their influence on interaction with people with disabilities and their exposure to HIV/AIDS.

In order to control my analysis for bias I sometimes let a friend/fellow researcher question my coding system. This provided me with alternative points of view but also with reassurance. As I only used case-studies for my research this thesis did not provide sufficient evidence of statistical populations but rather for theoretical proposition. It is also impossible to establish reliability and validity in the traditional sense. Throughout my research I tried to achieve validity through using multiple sources of evidence. In this sense the final results of the ranking exercise, the in-depth interviews and the focused group interviews were used for triangulation.

Reliability was approached with Burns’ understanding of qualitative research. He presses the point that reliability in such studies “is more focused on dependability and that the results make sense and are agreed on by all concerned” (Burns 2000, p. 475). The latter I tried to achieve with the focus group interview that I conducted.

PART II

CONCEPTS OF DISEASE AND DISABILITY IN KWAZULU-NATAL

4. DISABILITY IN KWAZULU-NATAL

This chapter will try to picture the macrocultural and microcultural setting of disability within KwaZulu-Natal. In this context historical as well as present developments have to be reviewed. The broader cultural system that surrounds Zulu-culture will be described in the first part of this chapter whereas the second part deals with the effects of marginalization and here in particular with the situation of women and people with disabilities. This is necessary to make the reader understand the double burden that women with disability have to carry.

4.1 AN OVERVIEW OF KWAZULU-NATAL

4.1.1 AN INTRODUCTION TO SOUTH AFRICA AND KWAZULU-NATAL

KwaZulu-Natal is situated in the South East of South Africa[1]. With its tropical climate, sandy beaches, berg getaway and game reserves as well as its rich cultural heritage, through the Zulu Kingdom, it is a very popular tourist attraction. Fertile land and the two biggest harbours in Southern Africa give KwaZulu-Natal the perfect setting for a flourishing economy. Despite this it is one of South Africa's poorest provinces with a high rate of social conflict and a significant gap between rich and poor. Much of this contrast is a result of South Africa's historical background.

Early History

Archaeological evidence suggests that the area around Pinetown, near Durban, had been settled by San or Bushman over 100 000 years ago, which Kaplan (1990) believes to have lived in the area until the 1800s. They are believed to have retreated from the Zulus into the Drakensberg, where Bushman paintings tell the story of those conflicts (Omer-Cooper 1994, p. 3). They were finally 'wiped out' in Natal by European settlers.

[1] The Appendix includes two maps of the study area.

The first Europeans to land on South Africa's coast were led by the Portuguese sailor Bartholomew Diaz in 1492. Five years later his fellow countryman Vasco da Gama sailed around Africa on his way to India. He reached what is today known as Durban on Christmas Day 1497 and named it "Rio de Natal", Christmas River (Omer-Cooper 1994, p. 18). It was not until 1652 that the Europeans and in this case the Dutch realised the strategic and economic importance of the Cape and established a colony. With the rapid development of the port at the Cape the need for labour increased. Firstly, slaves and politically banned people were imported from Indonesia (Java and Sumatra), but soon Dutch settlers arrived and immigrants from all over Europe followed. Because the demand for agricultural land, especially pastures, grew continuously, the settlement steadily spread from Table Bay towards the North and East. The indigenous people the Khoikhoi, also called the Hottentots, were forced to recede, although they strongly resisted the expansion of Cape settlers (Omer-Cooper 1994, p. 26).

In 1795 British ships landed at the Cape and annexed the colony to the United Kingdom (Omer-Cooper 1994, p. 36). With this they laid the foundation for century lasting conflicts between the Boers[2] and British. From the beginning of the 18th century the Cape settlers expanded their territory more and more towards the East. Around the area of the Fish river, which is today in the Eastern Cape, the then-so-called Boers encounter the Xhosas, who stood up ferociously against the European settlers (Omer-Cooper 1994, p. 37). The central government at the Cape was neither willing nor able to give the Boers efficient military protection. Absolutely incomprehensible to the conservative Boer communities was the approach of the British colonial government towards indigenous inhabitants of the colony, who were held as slaves on most of the white farms. From 1833 the slave trade was declared illegal and the "Emancipation Act" demanded that white masters set their slaves free against payment of a small compensation from the state. The Boers felt that the British policy destroyed their traditional social order which was based on racial separation and would undermine white predominance, which they saw as God's own will. In resistance to the Cape policies the Boers or Voortrekkers organised therefore what is historically called "the Great Trek", which started in 1835 (Omer-Cooper 1994, p. 52). The Great Trek was an organised migration of Boers with their wagons

[2] A cultural group of Europeans that descended from the Dutch. The are also commonly called Afrikaners.

to discover new land and to establish their own republics. The areas settled by these Voortrekkers are the provinces today called Gauteng, Orange Free State and KwaZulu-Natal.

A Boer excursion under the leadership of Piet Retief headed for Natal to gain land for settling and grazing. For this purpose they had to negotiate with the Zulu king Dingane. The negotiations ended with the agreement that the Boers could settle in central Natal. However when the delegates under Piet Retief prepared to leave, Dingane, who was suspicious of the new settlers, ordered his people to kill Retief and his colleagues (MacMillan 1963, p. 203). Then the Zulu warriors fell upon the rest of the Voortrekkers who had made camp at the foot of the Drakensberg to wait for the return of their leaders. About 500 men women and children were killed and most of their cattle stolen. With their newly elected leader, Andrew Pretorius, the Boers successfully consolidated in the aftermath and prepared for a retaliatory strike against the Zulu king. On the 16th of December 1838 the Zulus were completely defeated at the famous “Battle of Blood River” (Omer-Cooper 1994, p. 80). This enabled the foundation of a short-lived Boer Republic in Natal, with Pietermaritzburg as its capital. By 1842, British troops occupied Port Natal, today’s Durban, and annexed the hinterland as a Crown Colony (Omer-Cooper 1994, p. 85). The Voortrekkers retreated behind the Drakensberg.

The British had their very own encounter with the vicious warrior “tribe” of the AmaZulus. Records written by one of Natal’s first European settlers, Sir Francis Fynn, named tribes like the Amatuli and the Amanganga as tribes settling in the greater eThekweni area (Steward & Malcolm 1986). The Amaganga, who had fled from Shaka´s warriors were said to have sought refuge in the eThekweni area. At the time, through incredible atrocities and cruelties the infamous Zulu king, Shaka Zulu, gained control over a number of clans and united these clans under the Zulu name (Webb & Wright 1987, p. xvii). He expanded his territory systematically. Shaka´s warriors raided villages and burnt them down. The chiefs were tortured and forced into allegiance. At the beginning of the 19th century, Shaka had created the most powerful kingdom in the whole of Southern Africa. Eventually Shaka was assassinated by his (already mentioned) half brother Dingane in 1828, who in the aftermath succeeded him as well. For KwaZulu-Natal an irreversible process of

restructuring came to an end with Shaka´s death. Thousands of people had become refugees. Fights between European settlers, refugees and sub-tribes broke out everywhere (see Blood River) and all these disturbances led to regroupings. At the end of this period the small, widespread, chief led clans had disappeared and were replaced by bigger communities under the Zulu-kingdom on the one side and the European settlers on the other side (Webb & Wright 1987).

In 1879, the British laid claim to the whole of Zululand and gave king Cetshwayo a practically unacceptable ultimatum. In the resulting Anglo-Zulu War, the British initially suffered a high number of casualties. The battle of Isandluwana Mountain, on the 22nd of January 1879, was a particular disaster for the British, when the Zulu warriors overran the British army camp (Webb & Wright 1987, p. 34). Within a few hours almost 2000 British soldiers were killed (Omer-Cooper 1994, p. 115). At first this victory shocked the petrified British. England however decided to send more troops and the war ended in victory for the British in 1879 and Zululand was annexed by Natal. Two decades later the British would also defeat the Boers in the Anglo-Boer war (1899-1902) and with this annex the whole of South Africa as a British colony (Omer-Cooper 1994, p. 148).

After the Anglo-Boer War an increasingly large number of Africans withdrew their labour from European farmers in Natal. Zulu people found work outside Natal in the mines around Witwatersrand, which was more lucrative and attractive. By 1905 the situation became serious and in order to increase African labour in Natal, the government instituted a one pound poll tax on all males in Zululand (Omer-Cooper 1994, p. 153). This increased the financial burden of Zulu families who were already battling to overcome the effects of the Rinderpest from 1895-96 (Leclerc - Madlala 1999), which killed almost 90% of their cattle. Several Zulu chiefs refused to pay this tax and the Natal authorities sent out the police to collect the tax. A rebellion was led by Bambatha kaMancinza but despite initial success the tide turned against the rebel forces who were finally defeated in June 1906 at Mome, George. Between 3000 and 4000 Zulus and a couple of policemen were killed during the rebellion. In addition to that over 7000 Zulus were gaoled and 4000 sentenced to flogging. It is estimated that before the rebellion about 59% of Zulus were working in the mines but by 1909 it was 80% (Omer-Cooper 1994, p. 154). Men worked for a couple of months in the mines

and then returned for short periods to their families. The migrant labour system had been introduced to Natal and with this the African family structure destroyed. Labour from India was shipped in, to compensate for the shortfall on the sugar farms.

The Bambatha rebellion however remained in the Zulu consciousness and was never forgotten. Political leaders of the new South Africa, like Jacob Zuma, account the beginning of their political consciousness to their childhood when their grandparents would tell them the stories about the Bambatha revolt (Sunday Tribune 25.11.2007).

The African way of life was further infiltrated by the Christian religion that European settlers brought with them. One of the first mission stations in KwaZulu-Natal was erected in 1895 in the Mariannhill area near Durban (Bryant 1929). The conversion to Catholicism was rapid in the area. Other mission stations followed quickly. Missionaries usually planed to construct communities wherein the converted Zulus could settle and live "free of traditional restraints and tribal pressure" (Schimlek 1953, p. 16). For this purpose some churches even built proper villages around their mission stations in which only converted Africans were allowed to live. African custom was, for these missionaries, regarded as the key obstacle preventing Africans from converting to and maintaining a Christian way of life. In this sense they wanted to convert the Zulu villagers not only to Christianity but also to a farming life-style and monogamy (Leclerc - Madlala 1999, p. 84). Missionaries were also a driving force of formalising education, bringing schools to rural and underprivileged areas and installing a basic health and welfare system from which people with disabilities could profit as well. They would be a driving force of immunisation programmes and with this prevent disability and early child death to a certain extent. They however were also a driving force that undermined traditional knowledge with particular reference to herbal products and divine custom.

Another big influence on the African way of life was the progression of racial separations. Racial policies were introduced from 1910 through a group of laws that further restricted the rights of the black majority (e.g. 1913 Native Land Act). This later became institutionalised with the apartheid government in 1948 (Omer-Cooper 1994, p. 164). Laws like the Group Areas Act (1951) would restrict where people could live and socialise. The majority of South Africans, who happened to be

Africans, had to live in less than 13% of the country's land (Mandela 1994, pp. 114, 270). Marriage between races was forbidden (Prohibition of Mixed Marriage Act 1949). Africans had to carry a passport, also known as the dompass, that restricted them to certain areas. One of the most tragic results of the apartheid policies were forced removals where it was usually African people who had to resettle in homelands allocated for them. These homelands were usually small, under-resourced and far away from work. People had to live with uncertainty as they did not know if and when they would be removed. As people were unable to plan for their future they lost the motivation to look after their homes and communities deteriorated (Leclerc - Madlala 1999, p. 88). Some communities however managed to fight forced removal only to be disturbed by violence and civil unrest particularly in the 1980^{s}.

Passive resistance (Mandela 1994, p. 151) was organised right from the beginning and had its roots within the ANC and Gandhi's philosophy of peaceful resistance also known as soul-force or ´Satyagraha´. This however changed after the Sharpeville massacre in 1960, where the police recklessly fired on a group of peaceful demonstrators and bystanders (Omer-Cooper 1994, p. 209). This was the dawn of the armed struggle (Mandela 1994, p. 320). In this time the black consciousness movement under its founder Albert Luthuli grew as well (Omer-Cooper 1994, pp. 207, 220). This was a countermovement in which African people were called upon to be proud of their own culture and heritage rather than trying to be like Europeans. This movement has influenced black consciousness until today. The effects however of forced removal, the migrant worker system and an underprivileged education had already affected the African family and its way of life for many decades to come.

Today KwaZulu-Natal is one of 11 provinces in the new South Africa. The main population still consists of Zulu-speaking people. Indians and Whites make up a small percentage in the province. The population density is high as well as the unemployment rate. After the political system in South Africa changed from apartheid to democracy, heavy fights emerged between opposition parties (ANC[3] and Inkhata). This added to the province's long history of violence and social conflict.

[3] ANC – African National Congress

Recent developments

After the majority of white people expressed their will to change in a referendum in 1992 South Africa saw its first free elections in 1994. Nelson Mandela, as the president of the ANC, became South Africa's first post-apartheid president. Since then, South Africa has had to undergo a difficult period of transformation in the attempt to overcome inequalities and to give previously disadvantaged people a fair chance. The country had to invest heavily in infrastructure, housing and basic services, which is not an easy task with a limited amount of resources. Economically South Africa has developed in a variety of ways. While certain areas like the cloth industry struggle, other areas like the film industry and the property market have seen an enormous boom in the recent years. Particularly the latter is a blessing and a curse for South Africa at the same time. As property prices go up houses in the upmarket areas (for instance along the coast line) become unaffordable for South Africans, but at the same time South Africa gains foreign currency from overseas buyers, which it urgently requires. The result of these developments is that the gap between rich and poor has increased over time and the Gini-coefficient[4] of South Africa with 0,77 has risen and is now one of the worst in the world (StatsSA 2006, p. 3). Within South Africa the province of KwaZulu-Natal has the biggest poverty gap and with this the biggest division between rich and poor (see table 4.1). This situation causes social conflict.

Province	No. of poor persons (million)	% of population in poverty	Poverty gap (R billion)	Share of poverty gap
Eastern Cape	4.6	72%	14.8	18.2%
Free State	1.8	68%	5.9	7.2%
Gauteng	3.7	42%	12.1	14.9%
KwaZulu-Natal	5.7	61%	18.3	22.5%
Limpopo	4.1	77%	11.5	14.1%
Mpumalanga	1.8	57%	7.1	8.7%
North West	1.9	52%	6.1	7.5%
Northern Cape	0.5	61%	1.5	1.8%
Western Cape	1.4	32%	4.1	5.0%
South Africa	25.7	57%	81.3	100.0%

Table 4-1 Poverty indicators by province (HSRC 2004)

Another indicator of inequality in South Africa is the difference between the GNI (Gross National Income per capita) and the HDI (Human Development Index). While

[4] The Gini-coefficient is a co-efficient that describes a countries distribution of wealth. In this context 0 is regarded as complete equal distribution while 1 is the complete opposite. South Africa's Gini-coefficient of 0.60 is very high compared to other countries (Gillespie, Suneetha, & Greener 2007, p. 11).

the World Bank using the GNI is classifying South Africa as a upper middle income country the HDI has dropped in the last ten years to 0,695 (Du Toit 2002, p. 4 and 16) which brings South Africa in line with other developing countries like Indonesia. This difference is caused be unequal distribution of wealth, the population growth overtaking the economic growth as well as the results of the HIV/AIDS pandemic. Like most other African countries South Africa is faced with a relatively high population growth (StatsSA 2006). In addition to this the country is experiencing a tremendous amount of human traffic in terms of emigration and immigration. Unfortunately for the country's prospects this human traffic is imbalanced, as many professional people are leaving the country for better means and refugees, particularly from Zimbabwe and illegal immigrants from Mozambique and Nigeria are filtering into the system (Du Toit 2002, p. 8). This is an indicator as to the extent to which the country has become an exporter of skilled labour and a refuge for Africans of other nationalities during the last few years.

A high population growth coupled with a loss of skills would be detrimental to any country and places enormous pressure on government finance in terms of the provision of social services. The impact of HIV/AIDS on the democratic structure of South Africa has already become evident (see appendix 7). Life expectancy at birth has already dropped tremendously and is estimated to drop to 42 between 2010 and 2015 (Du Toit 2002, p. 6). KwaZulu-Natal has, out of all the South African provinces, already the lowest life expectancy with 49 years in 2006 (StatsSA 2006). In relation to the HIV/AIDS pandemic, stands the high prevalence rate of TB and drug resistant TB forms. TB is a particular problem in KwaZulu-Natal, because as a coastal province the humidity is much higher than in the rest of the country. This paired with a high HIV prevalence rate and poor health services provides a deadly cocktail. You will therefore not meet one person in KwaZulu-Natal that is not, to some extent, affected by HIV/AIDS or TB. Everybody knows someone in their family or labour force who is suffering from the effects.

As mentioned above South Africa had and has a notoriously violent colonial and recent history. An estimate of 20 000 people died as a consequence of political violence in the apartheid years between 1984 to 1994 (Wood 2005, p. 303) and even more people were injured or disabled for life. The country's complex political history

of tribalism, colonialism, industrialisation, apartheid and struggle against suppression has produced the conditions for violence of multiple forms to flourish. The extent to which both political repression and inter-personal violence have become pervasive aspects of everyday life, is being reflected in the daily newspapers in South Africa in which you find reports of crime every single day.[5] A dramatic legacy has also been left by the country's militarisation during the armed struggle against apartheid. Today townships and some rural areas are flooded with cheap, illegal firearms that are being used in cash-in-transit heists, hijackings or robberies, which in return cause death and disability in the country. Leading crime researchers like Antony Altbeker from the Institute of Security Studies in Cape Town, identifies "bad policy choices and government's failure to deal ruthlessly with criminals" (The Mercury, 12.07.2007) as responsible for fostering a culture of crime in South Africa. Altbeker explained that the wrong crime strategies were chosen based on the notion that prevention was better than cure and "that the police could be employed as armed social workers". In his analysis he points out that many of the decision makers today had suffered at the hands of the apartheid police and have therefore an "instinctive disliking for coercive law enforcement" and, I would like to add, an identity crisis of having to be on the other side of reinforcing the law. This however backfired allowing a violent culture to take hold and crime rates to explode in South Africa.

It took South African politicians a long time to recognise crime as a major problem in the country. Denial theories were even mixed with race issues as many white South Africans are able to leave the country in search of a safer place to live. The Minister of Safety and Security, Charles Ngakula even stated, in 2006, that there is no real crime problem and that anyone who does not like it "should leave the country" (wikipedia). In general it is believed that he was referring mainly to the white population as the ones who "can leave". White people are still sometimes pictured as the old enemy and their leaving did not seem to matter much. The Minister however had not assessed the situation of his ´black brothers and sisters´ who suffer even more from the crime in South Africa and often do not have the option to emigrate, therefore there was a substantial outcry to his statement. The identity crisis of South African leaders, who sometimes do not want to face reality and take over responsibility for crime became apparent. Only recently in the light of the 2007 ANC

[5] I have been reading the newspaper every day for the last 3 years and cannot recall a single day without a crime report in the paper.

election and in the aftermath of the murder of Lucky Dube,[6] the South African president Mbeki and the then deputy president of the ANC Jacob Zuma, have recognised crime to be of political importance and have promised to do something about the situation. Whether or not these are just empty election promises or if change will really occur remains to be seen in the future.

To summarise is to say that South Africa and especially KwaZulu-Natal is faced with tremendous development barriers as there is a high population growth, lack of skilled workers, high rate of unemployment, high HIV prevalence rates and high crime statistics. This background has to be kept in mind while reading this thesis. To give the reader even further understanding, the African struggle for identity shall be discussed in the next subchapter. This is necessary to make the reader understand the present context of disability in KwaZulu-Natal.

4.1.2 CULTURAL HERITAGE – FINDING ONE'S IDENTITY

In Africa in traditional times, the extended family wasn't just a thing, it was a very efficient organization whose purpose was to bring up children according to the ideals of the tribe. But, with the coming of Western Civilisation, if you wish to call it that, changes of an extremely destructive nature took place. In the modern town-ship no longer is the extended family allowed to live together. For example, only a certain number of people are allowed to live in a four room house. So whether he likes it or not, a man or a woman has to discard other members of his or her family and thus be without the important members of this beautiful organization which should assist him or her in the bringing up of children. Thus the extended family has been destroyed. (Mutwa 2003, p. 164)

Zulu people have an almost a legendary place in the history of KwaZulu-Natal. Their rise to power and hegemony more than 200 years ago under the leadership of Shaka Zulu has influenced history up until the present day. Zulu speaking people, especially, identify themselves with this military and political genius, who brought inter-tribal wars and unity to their ancestor's homes (Webb & Wright 1987, p. 6). Shaka Zulu is in this context often glorified for his military leadership and his crimes against humanity are ignored.

[6] Lucky Dube was one of South Africans most popular artists and musicians with international records. He was shot in October 2007 in an attempted hijacking at his home in front of his son. His fate is the fate of many South Africans and recently also visitors to the country. The murder of Lucky Dube, who was a prominent figure and fellow man, has made clear the fact that the rainbow nation of South Africa is facing major problems at the moment and that this can no longer be ignored.

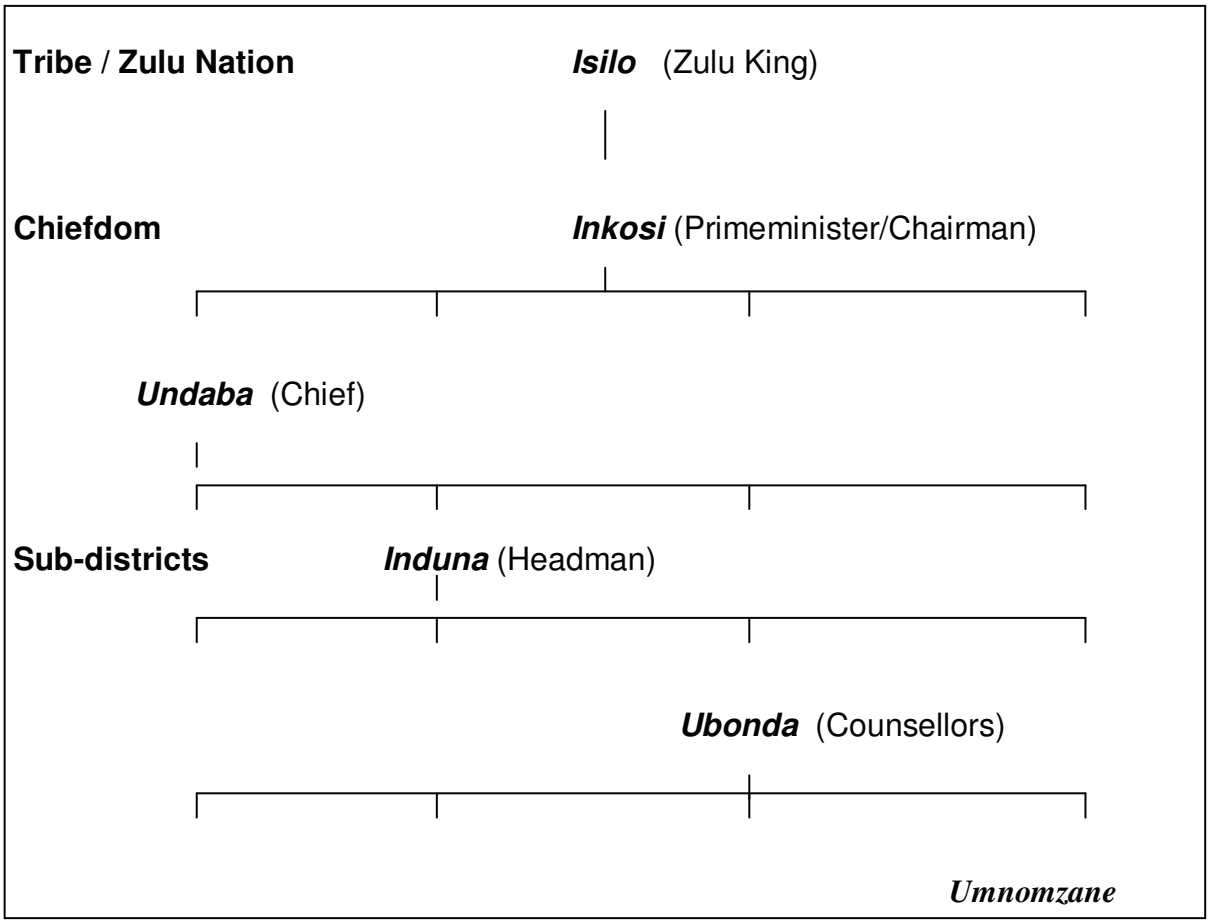
During the South African colonial and apartheid period, indigenous history was regarded as pagan, their leaders as barbaric and therefore historically not relevant. Today attempts have been taken to remember the Zulus as they once were, a proud, fierce and recklessly brave warrior nation who stood their ground in the face of a colonial power. Battles like Isandluwana 1789, where the Zulus defeated the British, and rebellions like the one from Bambatha in 1906, a revolt against the poll tax, are being celebrated in the new South Africa. However there is also a great resentment about the final annexation of Zululand into Natal in 1880 and the following suppression under the Colonial and later Apartheid government. The fast modernisation and intense political suppression has influenced the way of life of every Zulu speaking person. Christianity, Indian migration, the technical revolution, ´Western´ values, knowledge and culture have forever changed KwaZulu-Natal and the Zulu way of living, but this has not meant abandonment of all traditional ideas and values. In particular the basic patterns of family structure and neighbourhood relations have not yet totally changed and need therefore to be discussed.

Zulu speaking people belong to a Bantu group called Nguni (Omer-Cooper 1994, p. 8). The Nguni came down from central Africa into the area that is today KwaZulu-Natal and Transkei. According to archaeological evidence the eThekweni (area around Durban) region had been settled many thousands of years before by the ancestors of the San or Bushmen and later the Hottentots (1999, p. 82). As already explained they are believed to have lived in the area up until the early 1800s (Kaplan 1990) when they were expelled from their land by the stronger Nguni tribes that had arrived from the North. The San's last refuge in KZN was the Drakensberg and there the new European settlers finally pushed them out (Irwin, Ackhurst, & Irwin 1980, p. 43). The northern Nguni mixed with the Hottentots. From this cultural mix the Zulus have got the Click sounds in their language (Schapera 1946, p. 45). The San and Hottentots had been hunter-gatherers and nomads whereas the Nguni tribes were farmers. They sustained their life through subsistence farming (preserved for women) and cattle-keeping (preserved for men) (Bryant 1929).

In KwaZulu-Natal hardly any Tribe was fortunate enough to be left undisturbed in the early 1820´s during Shaka's regime (Webb & Wright 1987, p. 6). According to Sir Francis Fynn (Steward & Malcolm 1986), who was one of the first European settlers,

internal conflicts and systematic attacks by the warriors of the Zulu King Shaka, led to the demise of many tribes and so also of those ones living in the eThekweni area. Shaka Zulu, who is also called “the Black Napoleon”, united these tribes under his leadership and formed with this the “Zulu Nation”. In this nation different clans (isibongo – surname) are united. People who have Zulu surnames can be identified as having had an ancestor who belonged to such a clan. Examples of such names are Zondi, Zulu, Zungu, Ndlovu, Sibiya, Hadebe and many more. Some clans have developed sub-strains of names. A Hadebe for instance can also be called a Mthikhulu or Bhungane. To call someone by his sub-strain name is regarded as showing special respect for and interest in this person.

Clan members can belong to different Chiefdoms (isizwe), or all be a member of the same Chiefdom. A chief would be responsible for guiding the people of his Tribe according to Zulu custom and to report back to the king. He would be supported by the headman and counsellors in his villages (see feature 4.1).



Feature 4-1 Traditional social system of Zulu speaking people

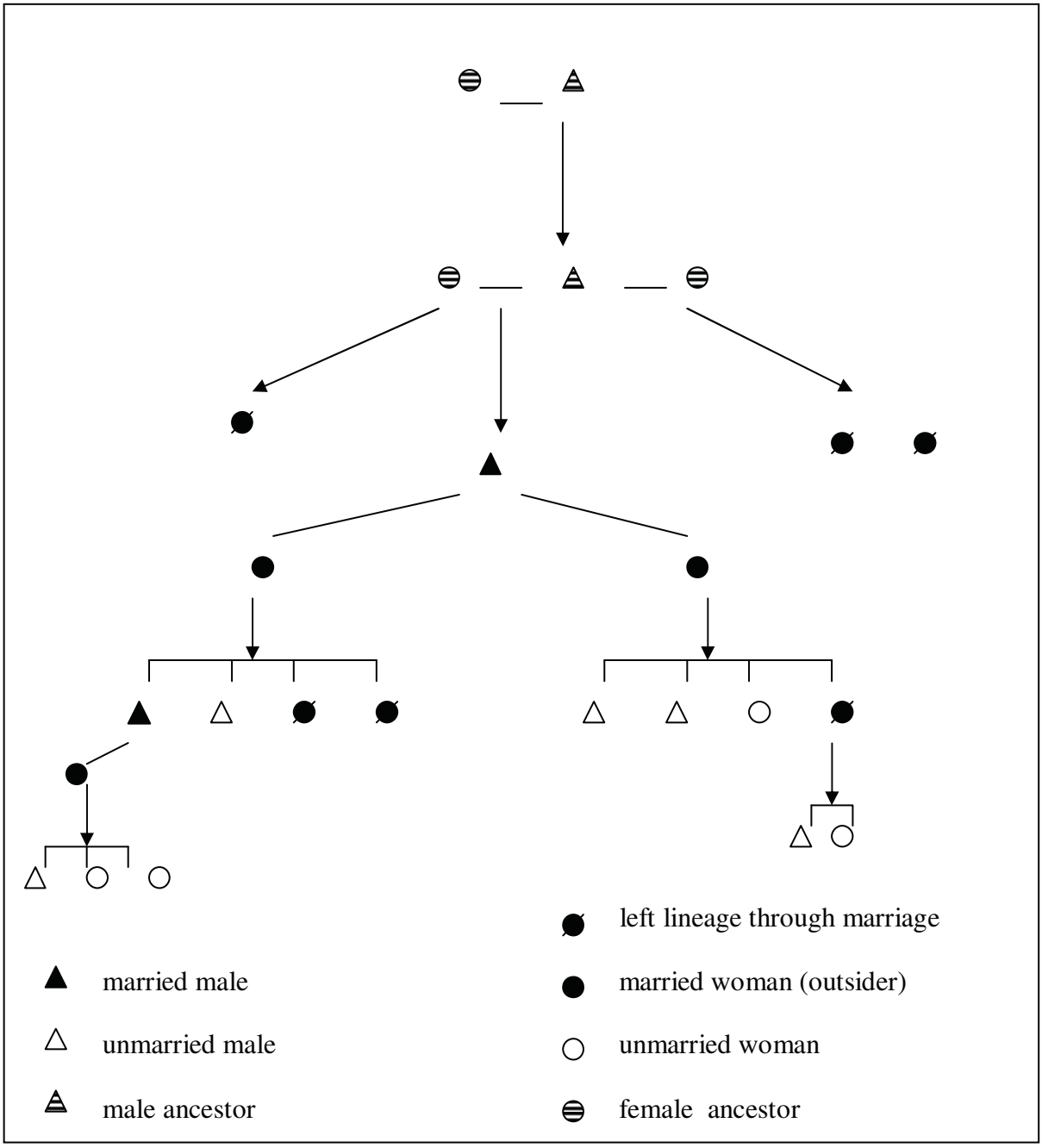
While one can inherit the position of a King or a Chief through one's bloodline, a headman is chosen by the Chief and approved by the people. A headman usually deals with tribal affairs. In the modern South Africa he is the traditional equivalent of the democratically elected magistrate, who is more responsible for service delivery and jurisdiction (Interview 6). However in a difficult tribal affair the headman would report to the chief, who often comes in, only periodically, from far away. He would then be expected to judge those cases.

Clans are divided into lineages[7]. A lineage is formed of people, who can trace descent to a common agnatic ancestor. Each lineage is divided into subgroups, who trace their descent down to a common paternal grandfather. This is the most important group in the linage and know by most Zulu-speaking people. Lineage membership is determined through belonging to a homestead head (Ngubane 1977, p. 13). This would be a married man, whose father and grandfathers are now deceased (see feature 4.2). A homestead may be composed of a man, his wives, children, and mother and could even include his brothers and their families if they have not yet moved out.

Lineage members have religious and social obligations to each other. In the case of death, special rituals have to be followed, especially for the homestead head. These rituals relieve the deceased's spirit into the lines of the ancestors. Zulu lineage is patriarchal and daughters become members of the new family as soon as the ´lobola´, the African bridal money, has been paid. They then become members of their husband's family.

In the old days and in very traditional families, lineage members of one subgroup will distinguish themselves from other groups by referring to their group as "Siwuzalo olidla ndawonye" - "the lineage members who eat with each other or who one sacrifices with". Ancestors are referred to as "Suwuzalo esingasadlelani nalo" - "the lineage members one does no longer eat with" (Ngubane 1977, p. 14). The former can be approached through sacrifices to help family members for different purposes and their worship is therefore very important.

[7] Lineage is in Zulu ´umndeni´ or ´uzalo´, which comes from ´zala´ to bear or with other words to be of common birth.



Feature 4-2 Lineage group

Zulu lineages are usually very shallow and most people remember their ancestors' names only up to their grandfathers. These are also the ancestors that will be worshipped after their death and held responsible for misfortune. Their influence can protect people or expose them to danger. If an abnormality occurs or if there is a disability in the family, then they could be held responsible for not protecting their own kind. They are also believed to watch their offspring's way of life and to either approve or disapprove of it. It is also said that they are especially interested in keeping African custom alive and expect their kind to follow traditional rituals like

paying lobola, introducing new family members and to relieve the deceased through sacrifices and so on. The prospect of losing the ancestors protection therefore puts substantial pressure on people to follow these traditions.

In the new South Africa it happens more and more often that young people turn away either partly or fully from their traditional way of life. Misfortune can then be explained through this ignorance. In recent years traditional leaders, some academics and political leaders have tried to strengthen African custom and put pressure on the re-evaluation of indigenous knowledge and its way of life. This has achieved much good for the recognition of indigenous knowledge.

The term tradition however is also often contorted to propagate certain people's points of view. Over time, a wide collection of so-called traditions have emerged. For example on the one hand King Goodwill Zwelithini proclaims virginity testing as an old Zulu tradition and Homosexuality as "UnZulu" (The Daily News 12.09.2005). The Zulu Shaman Credo Mutwa claims on the other hand, that men and women in traditional Zulu society were equal and the imagination of female inferiority is a "Victorian notion" brought by Western Civilisation (Mutwa 2003, p. 165). In my opinion these so-called traditions are contradicting each other. The "free" virginity testing of teenage girls which is aimed at controlling their sexual activity and the equality of the sexes can hardly claim to belong to the same idea. In fact, neither of them can satisfactorily prove that their claims are truly traditional.

The confusion about traditions is mainly a result of the ignorance fostered by the colonial and apartheid period in South Africa, that regarded traditional African life as pagan, inferior and not worthy of attention. Credo Mutwa argues, and not without reason, that the modern way of life has brought destruction to the African family and its spirituality. He sees this destruction as the source of all evil. (Mutwa 2003, p. 164). It is hard to know today, what life was truly like 200 years ago, because we can only base our knowledge either on books written mainly from a European perspective, or on verbal "hand over", African fairy tales and the dreams of spiritual healers. Especially in topics related to gender and sexuality it is difficult to argue what the real tradition was. Africans however long for this answer as they search for a common

African identity and consciousness. This leaves enough space for creativity but also for misinterpretation and misguidance of their cultural heritage.

One should rather argue that the African culture and the culture of the first settlers went into hybridisation and that some parts of African life have been reformed by western culture (Geertz 1983). In this process some cultural doctrines were given up while others were reformed and reinforced. The latter was probably the case in regards to gender relations and this shall therefore be one of the main themes to be discussed in the next chapter.

4.2 MARGINALIZED GROUPS

4.2.1 GENDER RELATIONS – THE SECOND CLASS

As a woman you are expected firstly to respect your husband and the other people, especially the male. Male person, it doesn't matter if it is your husband or your father or whoever as long as it is a father in the community … When you come in you greet other people and you know. You always have to have your face down. That shows the respect, that you respect older people. And it is not because you like to do it. You just do it. And you don't look at them in the eyes. … And you also have to work hard. Waking up early as a woman as early as maybe four o'clock in the morning, sweeping the garden or whatever, preparing tea, preparing the hot water for the rest of the family. So it is not easy. But because you have to, sometimes you are not even enjoying, but because you have to do it, you just do it. It is only now that things are changing a little bit, because people are more … especially people who are educated. So it is now, that you don't have to do everything for the rest of the family. Otherwise the respect, you still have to respect everyone. (Interview 2, mother)

Credo Mutwa claims, in his book "Zulu Shaman", that in the traditional Zulu society women were not believed to be inferior to men (Mutwa 2003, p. 164). This is however very difficult to believe, but also difficult to dispute as we have no written material about the Zulu way of life before the influence of "the Europeans". Africans often claim that anthropological writings by early pioneers of the field are full of "western" ignorance and do not understand the African way. So the only acceptable record that reflects the ancient African way of thinking about women seems to be African fairy tales and stories. The traditional Zulu stories, as told by Credo Mutwa, are full of suppression of woman especially in a sexual sense. For instance, in the Zulu creation story the first goddess Ninhavanhu-Ma is created from warm ashes and given to Sima-Kade, the Tree of Life, whom she despises. He holds the goddess

caught in his “arms” and fertilises her many times. Even though the great goddess is admired for her creational power, it seems to be acceptable that she was forced to bear Sima-Kades offspring’s against her will. One could also interpret this as a forced marriage followed by forced sexual intercourse, hardly what could be considered as gender equality, particularly not from a historical point of ´western´ emancipation, which created the awareness and vocabulary for gender equality.

However true or untrue Mutwa´s claims are about the past, the notion of women’s inferiority is well alive in KwaZulu-Natal today[8]. Within this the “traditional sexual script” (O´Sullivan, Harrison, Morrell, Monroe-Wise, & Kubeka 2006, p. 100), in which the man is the initiator and aggressor of sexual interactions and the woman is socialized to be passive sexually and accept or refuse men’s sexual advances, is still deeply embedded in KZN. Observers of the historical context note that the gender roles have become even more, rather then less, restrictive with time (Marks 2002). This conservative backlash is a result of decades of family destruction during the Victorian and Colonial era, the exposure to violence and abuse as well as the quick social change in which the younger population is perceived as uncontrollable and in need of discipline.

Under the cover of tradition, Zulu women are expected to obey their men. People often refer, here, to the word ‘respect’. The notion of respect is quite male orientated. This means, usually, that the household head, who has to be a man, makes decisions. A man is seen as the family provider and usually served by his family in their home. Traditional women, who are respectful, are expected to keep their eyes down and speak little. A participant explained it to me in the following way: Referring to his wife, he said that she respects him because she always accepts his decisions and does not start to argue even if a decision turns out later to be wrong (Interview 9). Many men seem to aspire to having a woman that shows them respect in this way. In this context, Leclerc-Madlala (1999, p. 126) explains that the biggest compliment a Zulu woman can get is that “she hardly speaks”. The desire to have an

[8] The imagination that women are inferior to men is still embedded in all main cultures in KwaZulu-Natal be it of European, African or Indian background. A shocking discovery I made while speaking to some High School boys in a single sex school in Durban. The class was culturally mixed, but many of the boys believed in stereotypes like: “women are inferior to men”, “a woman that wears a short skirt is asking for it” (It meaning sex) and so on. I also encountered these stereotypes on many occasions while speaking to adults. I even recall a group of college students laughing at the prospect of having a female president of the country.

easily manageable woman seems to lead to dubious relationships. One participant shared with me a story of a man who hoped to be with a deaf woman, because she would not argue. He believed this would be the perfect wife (Interview 1).

Women in very conservative families have to show their respect with the “Hlomipha” tradition (Schapera 1946, p. 74). In this case, women are not allowed to pronounce the names of the respected male members of their family and are required to use an alternative descriptive term, otherwise she would be very disrespectful. Women usually have to obey their husbands family customs as they are financially dependent on their husband. Traditionally a man also marries a woman from a far away village and brings her into his family. This puts women in a weak position. Leclerc-Madlala (1999, p. 123) presses the point that this is the very reason why women have a marginal and subordinate position and gives them a somewhat suspicious appearance.

In opposition to the previous case, one young interview partner had her very own interpretation of the word respect. She interpreted respect as the readiness to use condoms when one wants to have sexual intercourse (Interview 8). This was a very interesting answer and shows that some people start to change their minds about the way they interact with each other and transfer these conclusions into their private lives. This answer was however an exception and gender inequality and sexual dependency is rather the rule than the exception. As was found in the literature, some of my interview partners stated that it was very difficult for them to make sexual decisions. Their husbands or boyfriends decided when it was time for sex and if they would use protection or not. A fact that was also reported by many researchers in the field (Dladla, Hiner, Qwana, & Lurie 2001; Harrison, Xaba, Kunene, & Ntuli 2001; Leclerc-Madlala 2002; Preston-Whyte 1996).

Women in KwaZulu-Natal are responsible for the family. Most of the time they do all the housework and look after the children (Cross 2001, p. 140). They fetch water from far away, are the first to get up in the morning and the last to go to bed. Even if they are the main provider for their families they are still expected to do all the housework (Interview 6). They are very seldom supported by their husbands as housework is seen as woman’s work and it is embarrassing for a man to be involved

in it. The modern compromise is that the man will secretly help behind closed doors. Men are then in a strange dilemma as they develop different private and public faces. As soon as visitors are in the house he will put on his macho face and try to pretend that he can "control his woman". It is interesting that all my female interview partners were very critical and upset about the chauvinistic type of society they live in, while men had various views. Sometimes women were so frustrated that they refused to have a husband or permanent partner at all. They prefer to live on their own, even if that means that they have to provide for their children by themselves. The second type of woman, I experienced as very powerful, confident and amazingly aware of their situation. These were usually woman that had, at least, a small income of their own.

Interestingly, a number of interview partners described Zulu-marriage, rather as a financial arrangement, than as a matter of love (Interview 1). Dlala (2001, p. 81) found a similar notion in his analysis about women who are involved with migrant workers. In this study, it was found that women also enjoyed having casual partners on the side. Their affairs would open extra income streams and they could also enjoy "romance[9]" that they did not have with their husband or regular partner.

The cultural background of Zulu speaking people is influenced by the religious and cultural themes of the European migrants that settled in KwaZulu-Natal. The influence of Christianity has not helped liberating Africa's women either and seems rather to have had the opposite effect. While we know that African women, almost 200 years ago, wore next to nothing, traditional women today, have to cover their shoulders, knees and their hair. Without this they are not allowed into a kraal[10]. This is however, in strong contrast to the traditional dancing and celebratory performances where young women and girls dance almost naked in front of the king. The reason for the existence of two completely different types of dressing codes, which morally clash with each other but still have a parallel existence in the same society, remains a mystery and cannot be analysed in depth in this thesis. It is however very likely that the covered dressing code was brought in by Christian missionaries and that it was alien to Zulu culture before the "European influence". In the hybridisation of the two

[9] "Romance" is the local way of expressing "being in love", which is carefully differentiated from "making love" or having a sexual relationship
[10] A kraal is a traditional Zulu village or homestead

cultures some Christian values seem to have strengthened traditional stereotypes and in this case reinforced the suppression of women, who were now deprived of their natural and proud way of dealing with their bodies and had to develop shame and shyness towards nudity.

At the same time the new settlers introduced the concept of landownership, which was only allocated to men. This again robbed the African woman of her economic basis and reinforced suppression. The notion that a woman belongs to her husband and that the husband is the head of the household is a very Christian concept but also conforms to the deeper, culturally imbedded imagination, of a woman's inferiority.

Some Zulu traditions are very stubborn and immune to outside influence. ´Lobola´ is one such example. Traditionally a man has to pay ´lobola´ to his parents-in-law, before he gets married. Even though the lobola is part of a ritual that connects the woman with her new family, it is also a symbol of possession. Most participants explained that they would have to pay this bridal money, so as to refund the woman's family for the loss of an important worker. One cannot suppress the impression here, that women are unconsciously handled like objects which are passed on and have to be paid for. Because the man has paid a substantial amount of money for his wife, he can expect her to work hard and bear him many children. Women used to build up their status in society with the amount of children they would bear (Schapera 1946, p. 95) and still do.

In addition to this a man will not so easily divorce himself from a woman, he has ´bought´. Interestingly, most Zulu speaking people confronted with this interpretation about ´lobola´, would argue against it and say that African custom is being misinterpreted. For instance, one of my participants said that he and his wife manage the house equally. When I asked him who does the housework and looks after the children it was his wife only (Interview 17). Neither of them were working, but this did not mean that the husband would help in the house. The male perception that a woman has to ´look after her husband´ is very persistent and even affects woman in higher positions, like for instance a principal of a school. A study that was presented at a PhD seminar that I visited at the University of KZN in 2006, showed how difficult

it was for these women principals to fulfil their double role. Even though they would come home late, their husbands would sit watching TV or reading the paper and would still expect their wives to start cooking for them while they relaxed.

Historically, political decision making has been left to men. They hold all major positions such as that of chief and headman and only men participate in the political gatherings of traditional villages. Often the traditional handling of family affairs clashes with the constitutional rights of women, which brings traditional leaders in dispute with their democratically elected counterparts. This is one of the biggest challenges that faces the new government, whose intention is to balance the power of traditional leaders with that of government officials. The South African government is well aware of the fact that there is far too little progress when it comes to women issues and that women are still the main target of crime, abuse and unemployment. President Thabo Mbeki himself identified this as a "failure, where we see the fruits of our liberation have not reached many of our women" (The Mercury 10.08.2006). In other words, even though South Africa has gone through a great transformation, women are still regarded as second class and are being ´left in the rain´. Disability in this context adds another disadvantaging dimension.

4.2.2 DISABILITIES - PEOPLE IN THE PERIPHERY

Okay due to lack of education and all these other things that I mentioned before it all plays a big role in one not being employed. When one person thinks I am a punishment that person will never employ me in a company. I won't be able to get work and if one person thinks that I cannot see a bus when it is coming along that means I am always going to be coming late to work so that person won't really employ me. Also on all these other health issues like if they think a person with albinism is bad luck so if they employ them in their company they won't have any income coming. Lack of respect for them also results in them not being employed…. On education because of the problems that we face at school that makes you not be able to finish school and then obviously you won't be able to go to the technicon or university where you are going to finish and have a decent job for yourself. That is the basic thing. (Interview 17, man with cerebral palsy)

The disadvantaging and excluding consequences of disability are a phenomenon that has been well described around the world. People with disability find it generally more difficult to access basic support structures like health services, transport and education (Dederich 2007; DPSA 2001). As a result they are more likely to be illiterate, lack education, live in poor health, be unemployed and suffer from poverty.

Especially, in a country like South Africa, where so many issues emerge at the same time, the needs of disabled people can easily be forgotten. As a result people with disability become a marginalized group, whose issues seem to be only of minor importance.

In the 1980s, the Disability Right Movement was formed as a countermovement in South Africa. The foundation for this movement was laid in 1981 with the advent to the United Nations International Year of Disabled Persons (IYDP). South Africa's government at the time, chose not to recognise this year and disabled activists came together to discuss their marginalisation and oppression (DPSA 2001, p. 82). One of the outcomes of that meeting, was the realisation that the strongest "handicap" for people with disabilities was the view society had on them, as well as the weakening of people with disabilities as a larger group through medical orientated divisions in disability groups. Black people with disabilities were, in addition to that, facing a double stigmatisation of being black and disabled and organised themselves therefore in a broader organisation DPSA (Disabled People South Africa), which had close links to the liberation struggle. DPSA was formally constituted in 1984 and originated from local self help groups. One of such self-help groups was the Self Help Association of Paraplegics in Soweto, better known as SHAP. Its founding member Friday Mavuso, was the first disabled person that sued the then Minister of Police for his injuries. This resulted in him becoming an almost cult figure in the townships and an inspiration to people with disabilities in South Africa (DPSA 2001, p. 84).

His story is however the story of many South Africans, who were severely injured in encounters with police or in unsafe work placements. Many disabilities that are seen today have resulted from this. It did however, have a positive effect on people with disabilities. Similar to developments during and after WWI in Europe, disability became a broader phenomenon during the struggle years. As more people were affected by disabilities, than would otherwise have been the case, it was easier for the disability movement to claim their rights and make their issues heard in the new South Africa. Historically grown organisations like DPSA refuse the medical model of disability and advocate the social one wherever they can. Educated and organised people with disability in South Africa are therefore very aware of the social causes of disability. In their negotiations with the ANC in the 1990^{s} the disability movement and

here particularly DPSA, ensured that people with disabilities could finally speak for themselves and represent themselves in parliament. Inclusion, full participation and disability as a cross area issue, became the key areas of advocacy. It is therefore not surprising that policies like the White Paper[11] are very progressive on disability and inclusion issues and that disabled people are becoming members of parliament. The participation, as members of parliament through DPSA members, seems however to be bound on a membership of the ANC (DPSA 2001, p. vii). This makes the independence of structures like the one of DPSA somewhat questionable. Another unfortunate reality is that even though policies and intentions are very progressive, implementation has been very slow and hindered by lack of resources and education of staff (e.g. teachers, nurses, administrators). The progressive outline of policies has therefore not as yet reached its intention.

In their document, Statistics South Africa (2006) reported that a total of 2 255 982 persons had some kind of disability that prevented them from full participation in life activities. This number constituted 5% of the total population (44 819 778) approached during the research. The African population was reported as having the highest number of disabled people (1 854 376 or 5,2% out of a total of 35 416 166), followed by white (191 693 or 4,5%), coloured (168 678 or 4,2%) and Indian (41 235 or 3,7%) people as the table below shows. Statistics South Africa explains these percentage differences with the "variety of socio-economic and demographic factors, as well as unique social cultural perceptions and inhibitions with regard to reporting on disability. There are sectors that experience discrimination and exclusion more acutely than others.

Population group	N			%		
	Male	Female	Total	Male	Female	Total
African	879 680	974 696	**1 854 376**	5,2	5,3	**5,2**
Coloured	88 583	80 095	**168 678**	4,6	3,9	**4,2**
Indian/Asian	21 550	19 685	**41 235**	4,0	3,5	**3,7**
White	92 230	99 463	**191 693**	4,4	4,5	**4,5**
Total	**1 082 043**	**1 173 939**	**2 255 982**	**5,1**	**5,0**	**5,0**

Table 4-2 Totals and percentages of disability (StatsSA 2006)

[11] The White Paper is a government document about policies and in this thesis I refer predominantly to the section on inclusive education and disability.

African women with disabilities bear a larger burden of discrimination and exclusion compared to men and tend to have a higher rate of disability than the latter. This is primarily explained with women's higher average longevity. Another explanation could also be, that women in general have less access to resources which might result in higher prevalence rates on disability. The percentage of females affected was slightly higher than for males in the African and white population groups and slightly lower in the coloured and Indian/Asian population groups, as shown in table 4.2.

Disability in women is also seen as reinforcing traditional stereotypes of women being dependent, passive and needy (Seymour 1998). Women with disabilities are facing a double stigmatisation and are therefore:

- more likely to be poor and destitute
- more likely to receive less food
- more likely to be illiterate
- less likely to have the chances of founding a family
- more likely to be without family or community support (DPSA 2001, p. 37)

This applies to KwaZulu-Natal especially, as the gender gap in the province is high. As can be seen in the table underneath, this imbalance shows itself in the statistics for KZN. While other provinces have a relatively equal distribution of disability between men and women, in KZN there are significantly more women than men affected.

	N			%		
Province	**Male**	**Female**	**Total**	**Male**	**Female**	**Total**
Western Cape	96 549	90 301	**186 850**	4,4	3,9	**4,1**
Eastern Cape	173 229	199 037	**372 266**	5,8	5,8	**5,8**
Northern Cape	23 620	23 353	**46 973**	5,9	5,5	**5,7**
Free State	87 758	97 619	**185 377**	6,8	6,9	**6,8**
KwaZulu-Natal	219 685	250 903	**470 588**	5,0	5,0	**5,0**
North West	105 169	106 054	**211 223**	5,8	5,7	**5,8**
Gauteng	164 588	167 023	**331 611**	3,7	3,8	**3,8**
Mpumalanga	87 319	94 874	**182 193**	5,8	5,8	**5,8**
Limpopo	124 128	144 774	**268 902**	5,2	5,0	**5,1**
South Africa	**1 082 043**	**1 173 939**	**2 255 982**	**5,1**	**5,0**	**5,0**

Table 4-3 Disability distribution by province (StatsSA 2006)

Table 4.3 gives the number of disabled persons by province. It shows that KwaZulu-Natal had the highest number (470 588) while the Northern Cape had the lowest number (46 973). In terms of prevalence, Free State had the highest percentage (6,8%), while KwaZulu-Natal proceeds at the national average.

Conducting quantitative research for Disabled People South Africa (DPSA) Philpott (2005) explored living conditions of disabled people in KwaZulu-Natal, which to my knowledge is the only study available on this type of data in KZN. Most participants in Philpott's study had a family income of less than 1190 Rand, which is probably accurate as a large amount of them access social grants (780 Rand). However there was still a substantial group of people with disability that had no income or an income that was less than that of the social grant, which means that not all people have, as yet, access to this grant. Assessing people in rural areas, her data showed that only 46% had access to electricity, 64% to tap water, 29% had access to a pit latrine and 16% to a flushing toilet. These conditions make life for disabled people very difficult and also limit the use of modern devices that could be used to assist them. This may also be a reason why the community workers, whom I interviewed, frequently mentioned the hygiene problems that they encounter with disabled people in rural areas. In these areas they are often left to themselves, have no opportunity to access water to wash themselves and lack an assistant who can help them.

For people with physical disabilities even the most basic things like going to the toilet can become a major problem, for instance, when the doors are not wide enough for a wheelchair. A participant, being a community care worker, told me about a woman he recently visited and who was left entirely to herself. She never left the room and the smell inside must have been horrendous. Due to the condition of the room and herself, nobody was prepared to help her. In another case, an occupational therapist who worked in a rural area told me a similar story about a young man. He smelled so strongly and the situation was so embarrassing for his younger brother, the latter wanted his brother to be taken away to a care centre or at least believed that a separate room should have been built for him. Another participant explained proudly how clean he was and that even the nurses in the hospital would talk about this, because they had stigmatised people with disability as "dirty" and "smelly" and where astonished to see him being so "smart".

In Philpott's study, 78% of people with disabilities had access to public transport, but 27% of them stated that they had a problem accessing the road between their home and a public road. On the contrary, most participants in my study claimed that people with disabilities still had problems with accessing public transport (see appendix 16). The main problems that they seem to encounter are the impatient attitudes of able bodied people as well as the disability unfriendly design of transport vehicles. Access was a general problem that was reflected in most of my interviews. In a workshop I attended in August 2005, it was explained that people with disability had a major problem in accessing health services. While the local clinics, run by nurses, were better accessible, the transport to the hospitals was a major barrier. The transport problem is often a result of financial issues. Some people with disabilities have to have an assistant and therefore they have to pay the fee for two people. The trip to the hospital then becomes even more unaffordable. The district hospitals are however the only places that distribute assistance devices like hearing aids, wheelchairs and walking sticks. On top of this it is also possible for a person to have to travel to the hospital several times, because the hospital runs out of medication or the particular assistance device the person needs. Assistance devices like hearing aids or prostheses seem to be a general problem and also expensive. As one participant explained, he had been able to acquire a cheap prosthesis while he was in hospital after having lost one leg in a car accident. Now, after a couple of years, this artificial limb was falling apart and because he was not in hospital anymore he had no access to the subsidised limbs. On his own he could not afford a new one (Interview 25).

Other community services are also difficult to access for people with disability, because they do not cater for the special needs of these people and expect them to be able to wait in long queues and do not have interpreters or Braille available. Therefore some people do not manage to apply for an ID or for a subsidised house. One participant, for instance, told me that this was the very reason why he had to still live with his parents as he did not manage to line up at the registrar for the cheap housing (Interview 25).

The main people who could help to solve this contradiction seem to be community and CBR[12] workers. They have the local knowledge and are able to identify and support people in their homes. This is however only possible if they are at least supported with material. A participant explained to me that he has people who would like to help people with disabilities and HIV/AIDS in their homes. Unfortunately they battle to assist them with basic material, like gloves and bandages (Interview 22). So the problem lies, once again, with their financial constraints.

An interesting point in Philpott's study was that the most frequently identified problems were the lack of knowledge about rehabilitation (76 %), followed by knowledge about human rights (60 %), unemployment (60 %) and poverty (59 %). This order might also be a result of the type of questions asked. Most participants in the Philpott study might not have known what rehabilitation means and might therefore have identified this field as a problem. On the contrary my interviews showed very diverse results regarding people's awareness of disability and with this mirrored very different theories about disability. Even though I mainly used my ranking exercise as a tool to guide my participants through the interviews, it also reflected the interpretation process of disability (see appendix 16). After having studied the problem orientated ranking of my participants, a pattern began to emerge out of the data. Most professional people included in the study thought that access, poverty and sexual abuse were the biggest problems for people with disability. The male participants with disability often chose employment, attitude and respect and access as their main barriers. Women identified sexuality and abuse as the biggest problem followed by access problems and a lack of respect from their able bodied peers. These answers clearly reflect the different life experiences people in different positions have and how this influences their Subjective Theories concerning the phenomenon of disability. While the practical problems like access and poverty seem to dominantly impress professional people, humiliating factors influence people with disability more and are attributed with greater meaning. The different perceptions in accordance with gender, are also indicators for the different expectations with which women and men see themselves confronted. Men seem to experience their disability mainly as a loss in status as they find it difficult to fulfil their traditional role of the

[12] CBR – Community Based Rehabilitation a concept were local people assist people with disability. CBR workers are organized within DPSA (Disabled People South Africa), who also introduced the internationally successful programme in SA.

family provider and therefore lose respect in the community. Women on the other hand do not experience this pressure as much, but feel even more vulnerable through their disability than they would be as just a woman. Sexual abuse and a lack of access is therefore their dominant worry. This should be kept in mind in any project that aims at improving the lives of people with disability.

One such area where the attitude and excluding culture of able bodied people becomes most evident is sexual partnerships. People with disability very seldom have permanent partnerships and experience immense frustration in their sexual lives. The frustrations with sexual relationships are of a very different nature for women and men with disability. While a man with a disability finds it more difficult to find a permanent partner a woman with disability is, as previously described, very vulnerable to sexual abuse.

In her report, Philpott (2005) states that only 16 % of the participants were married or involved in any form of long term relationships. She questions, whether those low numbers are caused by the prejudice that disabled people are incapable of intimate relationships, or rather by their exclusion from society and the difficulty in meeting suitable partners. Dube (2004), who himself has a physical disability, also acknowledges these two factors as relevant. He also goes on to explain that physically disabled people have special difficulty exploring their sexuality, because often they need the assistance of other people, a requirement that is very difficult to fulfil in a society that has sexuality still covered under a big taboo. As a result of these factors my interview partners usually blamed the general negative attitude towards people with disability as the main excluding factor (Interview 2, 9, 22). Therefore partnerships might emerge within the “disabled community” itself.

Disability in KZN is often generalised. For instance the physically or sensorally disabled person is expected to have a mental defect, ignored and not taken seriously in discussions. Usually the assistant is addressed. People who know little about the impacts of disability conclude from one stimuli the abilities of the whole person. For example as Ngidi describes, his teachers did not know that his albino condition also affected his eyesight. He was placed in the back of the classroom and as a result

experienced learning difficulties and was then labelled as being stupid and lazy (Ngidi 2005).

People with disabilities are often pushed into the receiver role, a fact that one participant strongly criticised. Being treated as “helpless” and “cursed”, they learn to accept the fact that they are not able to do anything and have to rely on other people and social grants (Interview 7). As adults, this leads to a lack of initiative and confidence. In this way, people with disability seem to be groomed into becoming receivers rather then independent people. The receiver role is however not necessarily the easy way out, as people become very dependent on other people. They become dependent on their families and their assistants. They also become dependent on the good will of other people like those who organise their social grants. One of my participants had to leave her family to access her social grant, that was otherwise being used for the family and not for her. Another person could not access her social grant because she did not have the money to bribe the municipality worker into processing her application. The problem of bribing was also mentioned in a provincial meeting by the DPSA. Here a participant from Zululand explained that they even had problems with the doctors, who have to sign the form for the disability grant. One particular doctor charged an extra 150 Rand to fill out the form, something he was being paid for by the state. Besides the criminal element, one also needs to acknowledge that 150 Rand is a large amount of money for a disabled person who can only hope to get a maximum of 760 Rand a month from a social grant.

Another excluding factor for people with disabilities is the mystification of abnormalities[13] and the following chain of reactions. One example for this is the phenomenon of albinism. It always amazed me that some people in KwaZulu-Natal believed that people with the albino condition do not die, that they just disappear. Others were hiding them in their houses and another group of people would run to the other side of the street when they saw a person with the condition (Interview 1, 2, 16). Some people quoted that they have only very recently started to see people with albino condition, a fact that is probably caused by the habit of hiding these people at home. The first conclusion one could jump to is the fact that these people are hidden

[13] This will be further explored in chapter 5.

at home to protect them from the sun and that indigenous knowledge even though it was not scientifically founded did make sense for this particular person.

Only after exploring, very deeply, the hidden meanings that are attached to the abnormality of albinism and their interrelationships did I begin to understand the cause of these habits. While in the Xhosa tradition albino condition is regarded as a bad omen, in the Zulu tradition it means good luck. If albino conditions are interpreted as being a bad omen, people with this condition will find it difficult to apply for a job, be successful in business or find a partner. This superstition can go so far, that a person will change the side of street he or she walks on so as to escape this bad omen. If, on the contrary, the condition is interpreted as good luck, then the person's family will become very protective if not overprotective. The latter is especially relevant in the context of witchcraft, which is still embedded in the cultural context of KwaZulu-Natal. The possibility that someone could try to access "the albino luck" has caused people to be very suspicious. One is afraid that a child with albino condition could be abducted. If a person with the condition dies people fear that someone could come and take parts of the corpse to create a magical ´umuthi´. In an attempt to make this impossible, people with albino conditions are buried secretly (Interview 16). As a result the myth has evolved that they do not die and just disappear. For people with albino conditions this has very serious consequences. They find it difficult to operate in their communities and are, even though it might be for different reasons, excluded from various parts of social life. They might find themselves unemployed, be hidden at home or excluded from public places. They might also find it very difficult to find a permanent partner. This becomes especially relevant as people with albino condition seem to be used as sexual objects. Because of the obvious stimuli, some people develop an interest to explore them sexually. Sexual relationships are then started just to see how it is with a "white person" rather than having any serious intentions. This curiosity makes it very difficult for people with albino conditions to find stable partnerships and this causes frustration. Even though people show interest in their condition, the reasons behind it are often of a superstitious nature and do not contribute to a change from their position in the periphery.

4.3 CONCLUSIONS

This chapter attempted to explain to the reader the historic and current background of disability in South Africa and particularly in KwaZulu-Natal. Macroculturally disability issues in this part of the world have to be analysed from a historical point of view that emphasises that disability is only one of many issues the country is trying to overcome. As a young democracy South Africa is still a country that is looking for its African identity and position in the world. This struggle seems to sometimes distract political attention away from problems such as crime, HIV/AIDS and disability. The latter however often has its origin in political and social violence or through the marginalisation of disadvantaged groups of the population.

On a microcultural level women with disability experience a double burden and black women with disability need to be considered as particularly disadvantaged. One could speak of triple disadvantage. To live in a rural area could even add a fourth dimension. Women are suppressed into inferior positions. Having a disability makes them into a persona non grata. A woman with a learning disability might be accepted as a second wife, but ´lobola´ will be less or not be paid for her. A woman with a physical disability might find it almost impossible to marry. However if she finds a partner, negotiations for an equal relationship and safer sex practice might be even more difficult for her than it is for women in KwaZulu-Natal in general. Their lives seem to be dominated by the exponential function of finding a cultural identity as a Zulu-speaking person, a woman and a person with disability. All of which are a challenge in themselves.

Clearly this chapter shows that accessibility and service delivery still needs to improve substantially, so that living conditions for people with disability will improve. The statistics, as shown in Philpott's study need to be carefully analysed so as to understand the immense impact it has on people's lives. A disability taxi, for instance, could perhaps be a potential solution, so that people with disability could at least have access to hospitals and home affairs offices.

One must however also acknowledge that physical access and service delivery will only change a small portion of the excluding factors that people with disability

experience. The notion about people with disabilities being “unclean” or “stupid” and seen as “cursed by god” and unsuitable for a partnership, influences the social life of the person. These notions about people with disabilities shall be analysed and discussed in the next chapter.

5 CONCEPTUALISING DISEASE AND DISABILITY

Diseases and disabilities are predestined to become objects of everyday-theories, because they are manifestations of insecure situations. Moreover, they are a threat to one of the most highly regarded goods, namely health, and with this a threat to life itself. It is therefore not surprising that a great variety of interpretations and coping strategies have been developed, particularly in those cases of disability or chronic disease where medicine has little to offer. These interpretations are culturally embedded as well as personalised notions. Studies around the world about lay concepts, often also called "folk beliefs" and the special category of "cultural bond syndromes" (Good 1994; Mechanic 1982; Rivers 1924; Simons 1985; Turner 2000; White 1982), deal with peoples' perception of health and illness and reveal crucial factors such as pronounced fears of getting infected, attributions of guilt and the need to explain the sense and the special nature of the disease or disability. Beginning with a general definition of disability and a clarification of how the term will be used in this thesis, the following chapter will provide a deep insight into the way people explain disability in KwaZulu-Natal. The focus of this chapter lies within the microcultural and individual experience of disability (McElroy & Jezewski 2000, p. 192).

5.1 A CONCEPT OF HEALTH, DISEASE AND DISABILITY

5.1.1 THE SOCIAL AND CULTURAL DIMENSION OF BEING DIFFERENT

Concepts of health and illness stand at the core of social values and cultural influences because they give expression to many of our fundamental assumptions about the meaning of life and death. Disability within this discourse has been interpreted with different models, as there are the social, cultural and medical versions (compare chapter 2). It has been often argued that it is important, while studying how people in a particular society perceive and react to disability, to know something about both the cultural and the social attribution of the society in which they live. Culture is a term often used in explaining the different ways of handling disability. But what is culture? Helman (1994, p. 2), reflecting on various definitions, postulates culture as "a set of guidelines (both explicit and implicit) which individuals

inherit as members of a particular society, and which tells them how to view the world, how to experience it emotionally, and how to behave in it in relation to other people, to supernatural forces or gods, and to the natural environment". Culture in this sense provides people with guidelines to understand the world they inhabit and how to live within it. In the context of disability, cultural imaginations about an abnormal condition help to understand the condition and at the same time these notions can stereotype people with disability. As culture is not part of the natural world, so it is learned through the process of enculturation, the acquiring of a "cultural lens" through the process of growing up, and acculturation, the process of incorporating other attributes of a larger society.

The individual experience of disability, however, differs very much and there is a difference in the perception of disability between the people with disability and those without. This experience is conditioned by the way people behave towards the abnormal feature. Kleinman and Seeman (2000, p. 234) use the term "experience" to describe the "inter-subjective, felt flow of events, bodily processes, and life trajectory which always takes place within a social setting. Experience is the outcome of cultural categories and social structures interacting with psycho-physiological processes such that a mediating world is constituted". Cultural concepts of illness and disability experiences have taken a while to be accepted within the medial world. One of the first branches to incorporate the cultural concepts was the mental health sector. Cultural specification has attained a level of formal recognition in the field of medicine through the notion of cultural bond syndromes. Cultural bound syndromes are those types of disease or syndromes which can only be found in certain ethnic groups and are related to the local value and belief system, anorexia being one such example (Simons 1985, p. 26). In the mental health field the cultural influence has therefore already long been accepted and even found official recognition in the medical classification system within diagnostic canons like the DSM-IIIR or the DSM-IV[14]. It is therefore also not surprising that the results of Ethnography and the more political discussions around the field of disability studies have been recognised by international bodies like the World Health Organisation as an important tool in the design and analysis of successful strategies for intervention in the area of disability.

[14] DSM- Diagnostic and Statistical Manual on Mental Disorders

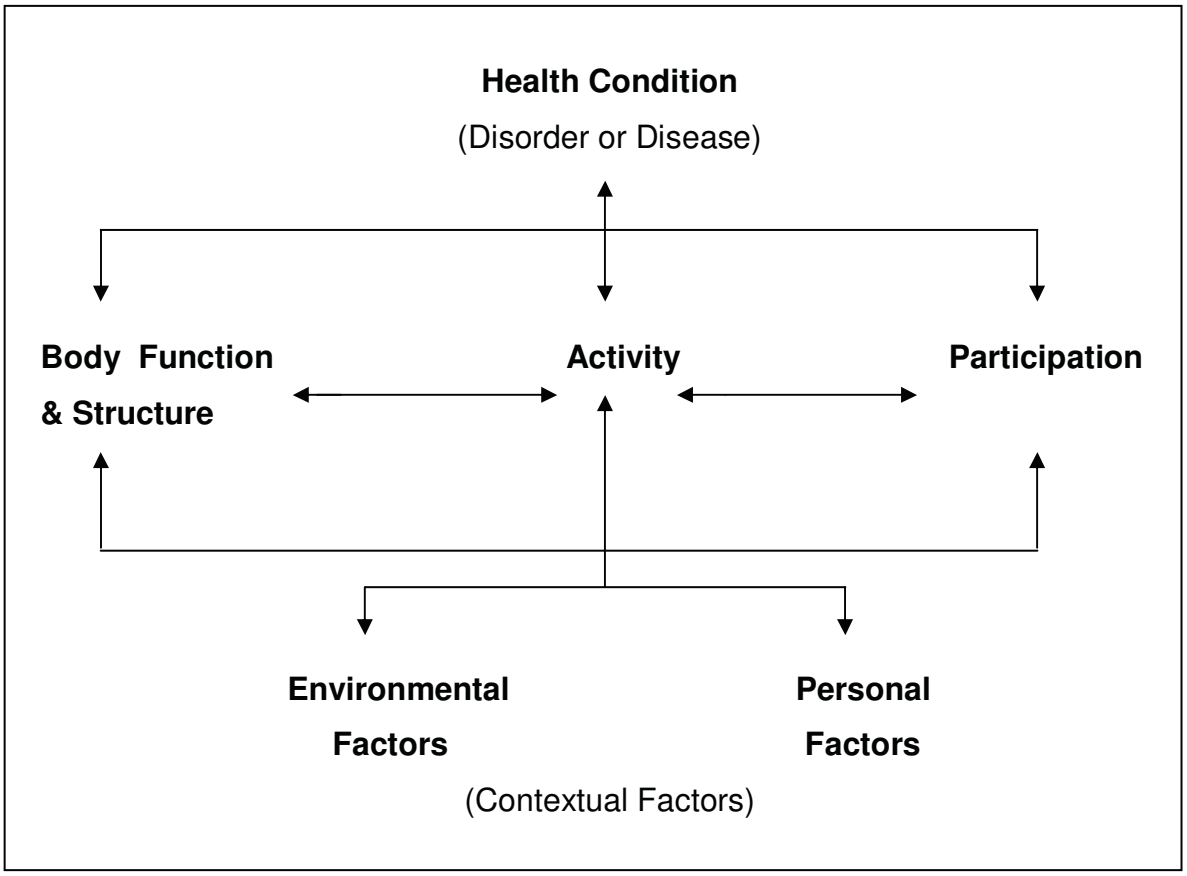
Over the last four decades, a gradual shift in the conceptualisation of health and disability from a medical model towards a combined model of disability has been carried out. The focus has moved away from a diagnostic based approach and towards a deeper understanding of the phenomenon of disability. This pays tribute to the realisation that a certain feature does cause different reactions in different social and cultural environments. On May 22, 2001, after nine years of international revision, efforts co-ordinated by the World Health Organization (WHO), the World Health Assembly approved the International Classification of Functioning, Disability and Health (ICF) (WHO 2002).

With this classification the world managed to synthesize the medical and social model of disability. Up until then the medical model viewed disability mainly as a feature of the person caused through disease, trauma or other health conditions which required professional medical care. Disability based on that model called for medical treatment or intervention so as to "correct" the problem within the individual. On the contrary, the social model saw disability as a socially-created problem and demanded a political and social response. Disability in this understanding is caused by physical barriers, personal attitudes and other features of the social environment. With the ICF both models were integrated into one "bio-psycho-social" model and this has paid tribute to the complex phenomena of disability (see figure 5.1).

Disability is now understood as "a complex phenomenon that manifests itself at the body, person or social level. According to this model these three dimensions of disability are outcomes of interactions between health conditions, other intrinsic features of the individual and extrinsic features of the social and physical environment" (Üstün et al. 2001, p. 5). The WHO model will be the basis of this thesis, as it sufficiently deals with the complex construction of disability and it is possible to explain the different reactions to the phenomenon of disability in relation to the social and environmental context.

Using the WHO model (see feature 5.1) a certain feature (body structure) like Albinism, can limit a persons activities. For example it would be the time one can be exposed to the sun without special protection. Provided the affected person has access to the necessary creams and lives in a country with less sun (environmental

factors) and in the case of visual impairments is offered the appropriate visual aid, then he/she will hardly feel any consequences of his/her disorder. This will be very different in a hot, sunny country, where the person is not provided with the necessary aid. The person might not be able to participate in many every day activities as he/she needs to stay out of the sun and might even suffer from loss of eyesight.



Feature 5-1 ICF Model of disability (ICF introduction guide p. 9)

If the cultural interpretation in a country stigmatises Albinism, however, then the person might experience exclusion to an even greater extent and be denied the opportunity to participate accordingly. Stigmatisation is usually based on presumptions about the affected people. These presumptions and the following reactions are often some of the reasons that make people with disability vulnerable to HIV/AIDS.

The model also includes personal factors like one's own attitude and the limits a person can set on him/herself. This could be caused by a lack of confidence or the adoption of the cultural interpretation of being useless because of the disability. Also

the feeling of loneliness and refusal can cause people to develop attention seeking behaviour, which in turn can be exploited by others. This exploitation, especially when it occurs in a sexual sense, makes people with disability vulnerable to HIV/AIDS.

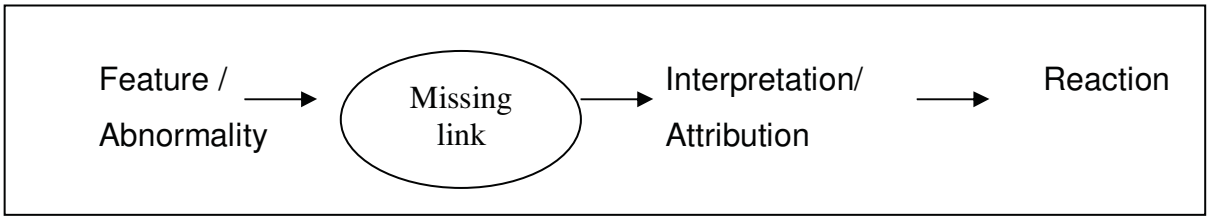
Extending the model one can also explain how a certain feature (body structure), that might not even be a disability in a medical sense, can be negatively interpreted and cause exclusion of the affected person. Depending on the cultural circumstances, features like red hair, skin problems or a certain skin colour have been described to have such effects. People react according to their Subjective Theories about the condition.

In the tradition of “meaning centred” medical anthropology (Good 1994, p. 52) however, one must critically remark that the model includes a mind-body dualism, that is alien to indigenous knowledge in Africa. Many anthropological writings, particularly those written in an “empiricist tradition”, are based on the separation of body and mind (Good 1994, pp. 38, 51). Soma (the body) is seen as juxtaposed to psycho, and disease as well as disability are attributed to the body. Contradicting this assumption, Good argues that “for the sufferer the body is not simply a physical object or physiological state but an essential part of self … It is at the same time a disordered agent of experience” (Good 1994, p. 116). Merlau-Ponty analyses, in this context, the body as the ultimate medium of experience and thus of our understanding of the phenomenal world. ”Sickness subjects man to the vital rhythms of his body” Merlau-Ponty wrote (1962, p. 172). Mind and body are therefore not juxtaposed to each other. In his phenomenological view, our body and its sensory functions correlate with each other. Indigenous knowledge often accounts for this correlation and therefore their cosmology does not know the separation of body and mind. A similar argument comes from the disability studies. Dederich (2007, p. 152) wants to include Embodiment into the theory about disability and in this way extend the bio-psycho-social model of the WHO. The concept of embodiment in this connection is used to press the point that disability is always a physical and social experience. Physical and social experiences are to be seen in mutual reference to each other, without prioritising one side chronologically, ontologically or logically.

For the reader, the WHO model is used to clarify how disability is caused through social interaction and environmental settings. In addition to this I will discuss disability as an embodied experience (Good 1994, p. 55) and the cultural issues emerging from that. For the emical understanding of disability another model will be developed further down. In this context it is necessary to look at the features, that decrease the level of activity and participation.

In Cloerkes (Neubert & Cloerkes 1994, p. 34) cross-cultural analysis of disability, comparing 400 different cultural studies, those features are called “Andersartigkeit” - abnormalities – (see appendix 11). He categorised reactions to certain abnormalities as universal (everywhere the same), inter-culturally variable, culturally uniform (in one culture the same) or intra-culturally variable (Neubert & Cloerkes 1994, p. 88). This may largely be due to the choice of Cloerkes’ samples, which are all studies conducted before 1980. The development of culturally diverse societies have, however, exposed people to a number of interpretative models, so much so that today’s results would be different, as cultural settings have moved on and different cultural explanations have hybridised to a more diverse understanding of the world. Studying my data I would rather suggest, that in KwaZulu-Natal reactions to abnormalities are inter- as well as intra-culturally variable and that people interpret and react according to their personal notions of disability. This notion however, is influenced by the person’s cultural background and the traditional explanatory models of the cultural group as well as personal experiences. Interpretive studies in medical anthropology have, particularly in the 80´s and 90´s, focused on the latter and created the term “embodied experiences” as the basis of illness representations. In these studies it is understood that history and social relations leave their “traces” in the body and as Pandolfi (1990, p. 255) writes, “this body becomes a phenomenological memoir that opens a new way of interpreting distress, suffering and illness”. Studies of the phenomenology of disease experience and “embodiment” have become ways of investigating the relation of meaning and experience as a subjective phenomenon (Frank 1986; Good 1994; Ots 1990; Wikan 1987). Researchers, however, often experience difficulties in representing suffering and subjective experience in ethnographic accounts as well as the relation between this experience and the local moral worlds (Good, Good, Brodwin, & Kleinman 1992; Kleinman & Kleinman 1991).

Even though the WHO as well as Cloerkes model accurately explain that the interpretation of a feature leads to a certain reaction, they cannot explain why and how people interpret this feature in the way they do. The link is missing. Cloerkes (1994, p. 87) even criticises this about his own study. He presses the point that the particular weakness in his study, is that they did not distinguish between the interpretation and the reaction to an abnormal feature. This link was missing.



Feature 5-2 Missing link in the interpretation process of abnormalities

Anthropological studies about "lay concepts" or "folk beliefs" have contributed to an understanding of this link in connection with diseases[15] (Good 1994, pp. 27, 39). Early anthropological studies and studies in the empiricist tradition (Rivers 1924) have used the models of belief and illness behaviour in this context. Disease and disability in this tradition is understood as part of nature, external to culture. Differences form the rationality of the physician and are seen simply as the result of lack of information or "superstition", through which "false belief" unfolds. Belief is seen as a false proposition, juxtaposed to medical knowledge[16] causing adaptive strategies and choices that might contradict "rational" behaviour. Belief in this context served as an unexamined proxy for "culture". Correcting these "false beliefs" is and was the top priority of public health in the so-called "western world" as well as in the colonies (Turner 2000, p. 10). The offensive language and the arrogant way of presenting biomedical knowledge as superior has caused problems up until today, where attempts are taken to acknowledge indigenous knowledge[17] (Ashforth 2005). However critically one analyses these early studies (Good 1994, p. 38 ff) they have contributed by explaining why people in a different cultural context react to the same biomedical phenomenon differently. By the same token they can not explain how these ´beliefs´ evolve and how they fit into the broader cultural context. Going one

[15] As mentioned before disability studies often lack this link.
[16] One notices the use of language in connection to "belief" and "knowledge".
[17] This is however sometimes very difficult as indigenous knowledge has to be "digged out" of its suppression. What one finds is not always the indigenous knowledge but a desperate charlatan.

step further, cognitive anthropology has taken the attempt to understand lay concepts from an indigenous perspective. Frake´s classic study among the Subanun of Mindanao was conducted without the reference to biomedical categories. He purely argued that the “emic” understanding of disorders and diagnosis is a “pivotal cognitive step” in understanding lay concepts (Frake 1961, p. 132). Studies following his tradition identify indigenous illness categories and use these for further studies (Fabrega & Silver 1973, pp. 135-140). An important step for cognitive anthropology was also the evaluation of indigenous knowledge as such and with this bringing it out of its dubious corner of “belief systems”. Cognitive anthropology also found that the causation is often more closely linked to treatment than are the symptoms (Good 1994, p. 53). This proved to be an important discovery as it gave a deeper explanation why people interpret disease and disability differently from the biomedical view, which interprets disorders based on the symptoms. As it will be shown later, the notion of disability and disease in KZN is also deeply affected by identified causes. Cognitive studies of illness representation are also serving increasingly powerful critics of many generalised accounts of health representations and assumptions that “cultural beliefs” are consensual. With other words, illness representations are influenced by culture, but different people can come to different conclusions.

Some authors also see illness and disability representations as culturally constituted realities (Good 1994). In the juxtaposition to the empiricist tradition, they placed the relation of culture and disease/disability in the centre of their analytical work. Good argues that disease in this tradition is “not an entity but an explanatory model... Sickness is constituted and only knowable through interpretive activities” (Good 1994, p. 53). In this interpretation people have, as Good calls them, developed “semantic networks” (1994, p. 54). These “constitute illness as a syndrome of meaning and experience.” His research also suggests that these “networks of associative meanings link illness to fundamental cultural values of civilisation, that such networks have longevity and resilience, and that new diseases (such as AIDS) or medical categories acquire meaning in relation to existing semantic networks” (Good 1994, p. 55). Beside semantic networks, the already mentioned “embodied experience” influences a persons interpretation of disease and disability. How these “semantic networks” and “embodied experiences” unfold themselves has to be

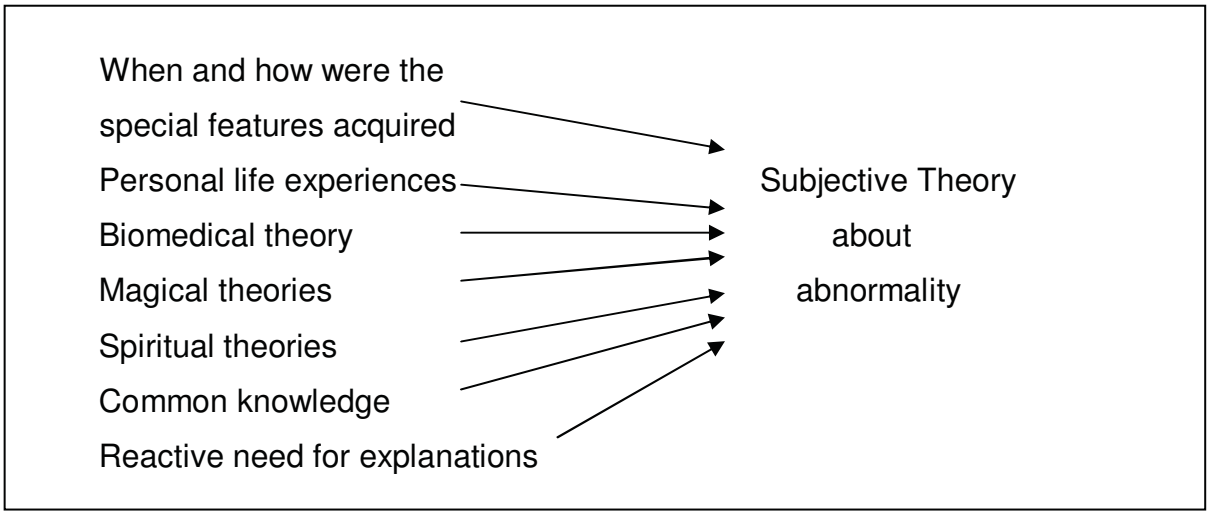
discovered for every cultural background, community and individual. To understand how the individual acts in these networks an excursion into psychology seems appropriate at this point.

5.1.2 SOCIAL REPRESENTATIONS AND SUBJECTIVE THEORIES

Dederich (2007, p. 43) argues that the disabled body is not a physical object but rather the result of cultural attributions and social reactions. As discussed in chapter 2, the theory of Social Representations and Subjective Theories about health and disease may be used to explain, how people interpret disease in accordance with their cultural heritage, their individual situation and their life experiences. Due to the fact that disease and disability are closely related to each other (Neubert & Cloerkes 1994, p. 33) I have chosen this theory to explain the interpretation process of culturally relevant, abnormal features. Those features that are regarded as being different in a certain cultural context, I will call abnormalities. Abnormalities that effect a person's social interaction shall be understood as disability. My particular interest in this regard is focused on the notions people have about abnormalities, what attribution they give to the causation and how these attributions evolve.

In general, attributions are the result of an interpretation process (Hewstone & Augoustinos 1995). This process is initiated through confrontation with an abnormality. Only if an abnormal feature is noticed as ´out of the norm´ the need for explanation will emerge. Room labels this level "thresholds" (2001, p. 262). In their cross-cultural analysis, Room (2001) demonstrates that there are considerable variations between cultures and the set threshold at which a behaviour or condition is defined as problematic or may not be noticed at all. Thresholds can also exist on various levels and, as the authors argue, there is a threshold for a condition to be noticed and another one for it to be classified as a disability. The threshold level might also be influenced through functional aids, environmental modifications and the social acceptance of diversity. What might otherwise be a big problem, can under different social settings, be only a minor issue. Thresholds are, in other words, socially and culturally influenced and they in return influence the need for explanation and with this the need to build up Subjective Theories about a condition.

Subjective Theories are defined as an aggregate of thoughts about the self and the world. They are theories explaining phenomena around us with an implicit argument structure, that is comparable to scientific theories (Groeben & Scheele 1982, p. 16). These theories help us to interpret phenomena, provided we need an explanation. This need only occurs when we notice a phenomenon or condition as unusual or threatening. The threshold for this can rely on different levels of intensity and values. In social settings that are predominately influenced by the scientific revolution, the symptoms and physical characteristics of a person will determine if a disease or disability is noticed or not (see feature 5.3). In societies where the magical world and myths still play a substantial role, Social Representations of the causes of disease and disability may play a stronger role in the interpretation process and overshadow the actual symptoms of the condition.



Feature 5-3 Subjective Theories about abnormalities adopted from Becker (1986)

In the interpretation process certain determinants play a role. Personal life experiences (also embodied experience) as well as the necessity for an explanation (what happened, why me or why him?) influences if and how a person looks for answers. In the attribution process people are influenced by a variety of variables that depend on their social, cultural and educational background. People could explain abnormalities with a biomedical, spiritual, magical or a common approach and so find their individual answer as to why a particular person has got a particular feature at a particular time in his/her life. This individual answer is a Subjective Theory. Subjective Theories are influenced by Social Representations about the conditions. In other words the notions about a condition that are common in the

person's environment, influence to a large extent the person's own theories about a condition.

Referring to Moscovici, Social Representations are certain, re-occurring and extended models of images, notions, beliefs and symbolical behaviour, which are common in a certain social community (Moscovici 1995, p. 310). They are a system of values, ideas and behaviour that wants to create order and enable communication. Under a more static approach, Social Representations can be seen as theories that summarize and bring order into a particular topic (e.g. women are inferior). As a consequence these theories offer common value systems and widely accepted behaviour patterns (women do the minor work, while men are the boss or manager). Under a more dynamic view, Social Representations can be seen as networks of loosely connected concepts, metaphors and images which are, because of their loose connection, more flexible than scientific theories. People carry these concepts, metaphors and notions with them and base their interpretation of the world on them, often even unconsciously. Moscovici in his interpretation of Levi-Bruhl's work has postulated that there are Social Representations in modern and pre-modern (they use the word ´primitive´) cultures but that they differ in their social significance. According to Moscovici the differences lie within the following few points.

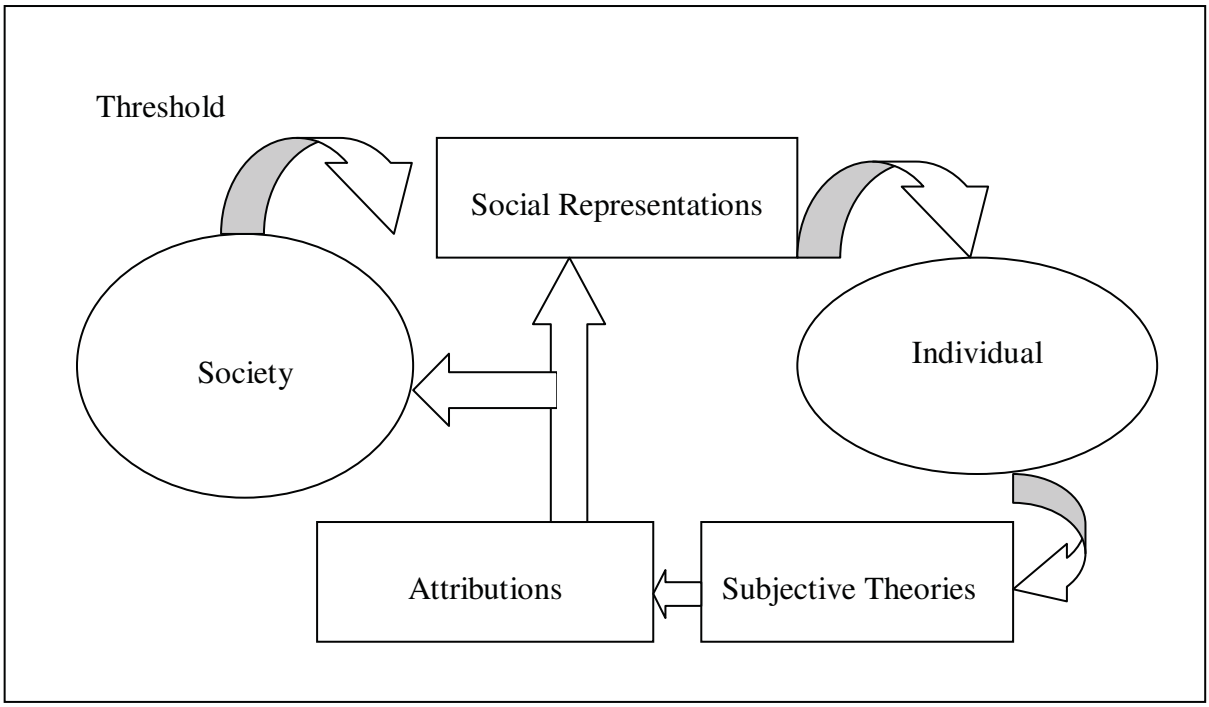
- Representations are intermingled with emotions. Particularly in so-called "primitive societies". Therefore these representations do influence the effective bonding and interpretation of the person that the representation is about.
- The social implications and causations are often more significant than in modern societies.
- People in pre-modern cultures have less difficulty including contradictive elements within explanation models, than those who have been strongly influenced by the scientific approach of the modern world (e.g. combining scientific knowledge with magical notions). (Moscovici 1995, p. 286)

The point that Moscovici wants to press with such a comparison is that Social Representations in pre-modern and modern societies differ, that they value different

aspects differently, but that this does not mean that the one is inferior or superior to the other.

Social Representations are often seen as the basis for social attributions and Subjective Theories (Hewstone & Augoustinos 1995, p. 81). I want to use them here as a tool in explaining the link between the threshold of noticing abnormality and the attributions that are connected to disability.

Every culture has culturally and socially accepted explanations or Social Representations. Based on these Social Representations and a person's individual situation, Subjective Theories are formed and assumptions about characteristics and causations emerge. These assumptions or attributes focus on personal or situational factors (Hewstone & Augoustinos 1995, p. 79). As Social Representations are influenced by culture, it is not surprising that Hewstone and Augustinos concluded that people in ´western´ cultures tend in general to overestimate the individual factors (1995, p. 81).



Feature 5-4 Inter-relationship between Social Representations, Subjective Theories and Attributions

Both authors researched Social Attribution in `Western Societies´ or modern societies. As these societies tend to be more individualistic it is not surprising that attributions to disease and disability tend to be on a more internal, personal level. The attribution process in another cultural context, particularly one that focuses less on individual development and more on the ´survival of the group´ or has a rather holistic approach to life, could look very different. The so called “Attribution-mistake” could fall on the other end of the spectrum.

5.1.3 ‘WESTERN’ VERSUS ‘TRADITIONAL’ CONCEPTS

In medical anthropology the ‘western” and ‘traditional’ world are often shown to oppose each other, the one being scientific and the other spiritual or magical (Finkenflügel 1999). The dualism of western versus traditional medical concepts is problematic for many reasons. It forces people to choose between the two and does not show the diversity that medical systems have to offer. However, in the time of globalisation and cultural diversity, it is debatable if there is still such a clean cut between western and traditional medical systems and if they are really as opposing as so often shown. Turner (2000, p. 10), for instance, describes that even though the European Renaissance lifted the myths of many diseases, medical notions still continued to evoke and be connected with paradigms of moral behaviour and a search for the answer to the critical question “why me?”. This question is often thought to belong to pre-modern culture only. For this very reason it is often argued that even though Africans will consult a ‘western’ practitioner for symptom treatment, he or she might also consult a traditional healer to look behind the reason of the disease or disability (Nattrass 2005b, p. 167). In modern times, however, the western world has also posed this question, which shows that we are not so different after all. The opposite is the case if one uses Moscovicies theory of Social Representation and his explanations about “modern” and “pre-modern” (primitive) cultures. The so often emphasised difference between the two “blocks” of culture is probably not an absolute one but rather a gradual one. As described earlier (see chapter 5.1.2) people in pre-modern cultures have fewer problems with incorporating contradicting elements in their theories about disease and disability. Theories are more emotionally filled and the causation of the condition is attributed with more meaning than the symptoms. As a result people do not only want to overcome the symptoms

of a condition, but they also want to know why they were affected at that particular time. People in modern cultures will also ask such questions, but to a lesser extent. In addition to that, people in pre-modern societies will not see it as contradicting to consult a traditional healer and a medical doctor as they attribute different practical skills to the two professions and therefore look for different advice from each.

In addition one can argue that in the African medical system, different experts exist for the various diseases in the same way as they do in the so called 'western world' (Bichmann 1995, p. 46). There are the bone readers, the spiritualists, the shaman (herbalist, sangomas) and witchdoctors. Each of them could also specialise in certain problems and diseases. In the so-called 'western world' one also meets various specialists like general practitioners, psychologists, physiotherapists, alternative health practitioners and many others. The difference here is that these practitioners are professionalised and their services and treatments have to be approved by science[18]. Traditional healing practice, also often referred to as Indigenous Knowledge Systems (IKS), have been undermined under the colonial and apartheid regime in South Africa. The present government has undertaken attempts to uplift its status. This however is often done through pressing the point that IKS is different from other medical systems. The use of the term IKS in post apartheid South Africa is more than ironic. As Ashforth (2005, p. 221) points out, the term and its surrounding programmes postulate the notion of cultural distinctiveness that the architects of apartheid would have found most agreeable.

Recognising this diversity in 'both worlds' one must press the point that a pluralistic understanding of health notions seems to be more appropriate. Recognising this understanding Bichmann speaks of "medical pluralism" and "parallel medical systems" within one culture (Bichmann 1995, p. 47). One therefore needs to appreciate that people use a number of different concepts, that are available in their contextual circumstances and that these concepts influence their "semantic networks" (see Good above) and with this ultimately the individuals Subjective Theories about disease and disability. One could also speak here of a hybridising of culture. This approach seems especially appropriate during a time when people are

[18] Science in this instance is understood as a reasoning with facts, the intellectual and practical activity encompassing the systematic study of the structure and behaviour of the physical and natural world through observation and experiment.

exposed to different ideas. In the new South Africa you cannot categorise people as belonging to a modern or pre-modern society only. People have moved on and in some ways live in ´both worlds´. Notions about disease and disability are therefore built up on the basis of various knowledge. Subjective Theories are influenced by scientific as well as magical Social Representations alike.

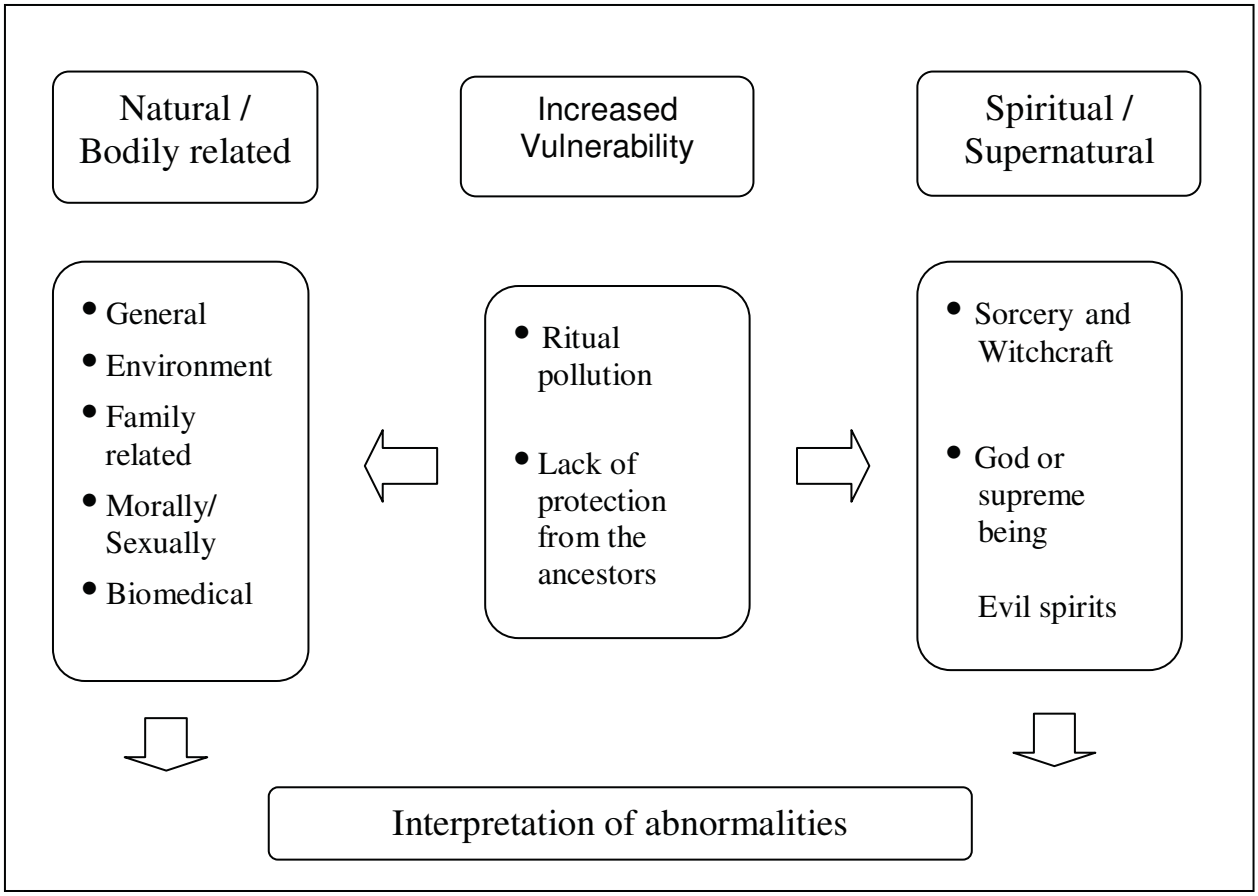
Exploring traditional African thought, especially that of Zulu-speaking people, writers such as Callaway (1870), Krige (1944, p. 63), Ngubane (1977, p. 23) and Leclerc-Madlala (1999, p. 182) reconfirm that imaginations about misfortune involved the question about how and why. The answers to the "how" question are usually based on common sense and empirical observation. For example, a person is run over by a car and as a result is therefore left disabled. A person has sexual intercourse with many people and therefore gets infected with HIV. People do not necessarily dispute these immediate causes of misfortune, but do look for a deeper explanation and the answers to the "Why" question. The question is however about: Why me?, Why here?, and Why now? The answers to this are slightly more elusive. I want to press the point again that people in both the so-called 'western' as well as in the 'traditional African' societies ask these questions. The difference lies in that African people have different answers to these questions. So-called 'westernised' people might tend more often to search for a scientific explanation or look for an answer in god, the concept of stress or simply astrological attribution. African people also have other choices, which will be described later.

During my field research I have found that most people in KwaZulu-Natal roughly categorise the cause of disability into two groups being either natural or spiritual (also supernatural see feature 5.5). Natural causes are understood to be everything that happens without the influence of witchcraft, a superhuman being or a spirit. Disability caused through spiritual influence will be explained with the latter.

These rough categories are very similar to findings by some of the first medical anthropologists like William Halse Richter, who categorised interpretations of diseases into "magical, religious or naturalistic" (1924). Richter's magical and religious categories may as well fall into one group as they both assume a supernatural being or power. It is interesting to note that the first anthropologists

were describing the magical world of indigenous people as superficial, while they were "blind" to their own magical interpretation, which they named religion in the attempt to distinguish themselves from people that they believed to be primitive.

Diseases or disabilities of a spiritual or supernatural origin are traditionally described as "African diseases" and it is general knowledge that they can not be healed with any "western type of medicine" (Ngubane 1977). Interestingly enough it is not the origin of the substance that makes it an African medicine, but rather the person who prescribes the so called "umuthi" and the fact that certain rituals have to be followed. Some of these substances may even be imported from China, but prescribed by a traditional healer and hence it will be considered an African medicine.



Feature 5-5 Diversity of Social Representations about the cause of abnormality and/or disability

Depending on how the cause of the disability is interpreted, a person will seek advice from different practitioners. If the cause is interpreted as being natural then the person will approach a biomedical doctor or a herbalist. The latter is commonly regarded as being a traditional healer. If the disability is however believed to be a

result of witchcraft or neglecting traditions then a person would consult only a herbalist or alternatively a sangoma. Herbalists also often specialise in certain diseases and disabilities. If the disability is believed to be caused by witchcraft or spirits then one would consult a shaman or sangoma (a traditional spiritual healer). Often Africans visit their local herbalist first to find out what may be the reason for their suffering and which person they should consult. In the case that the disability is believed to be caused by a curse of god one would not necessarily go to a herbalist and rather choose a church and prayers.

In KwaZulu-Natal the concept of being vulnerable or dangerous influences the explanation of the causes of diseases and disabilities. Vulnerability is often associated with pollution, a stage where a person is seen as dangerous and weak at the same time and is often associated with the female production system, birth or death. Precautions have to be followed, strengthening “umuthi” can be taken and protecting rituals need to be conducted.

I have found that people follow different routes in their interpretation process of abnormalities and that hardly any presumptions can be taken as to how a person will react under certain circumstances. I rather argue, that a person chooses a way to interpret an abnormality/disability in accordance with the Becker model (see figure 5.3). It is therefore also possible that a person approaches traditional as well as biomedical health care for the same condition, hoping the one would deal with the spiritual causes and the other cure the symptoms. Besides the natural and spiritual interpretation of disability there is a growing number of people that base their interpretation of disability on a social model. They are usually well educated people and often disabled themselves or work/live with disabled people. These notions and interpretations, thus Social Representations, shall be described in the following chapter.

5.2 THE NOTION OF DISEASE AND DISABILITY IN KWAZULU-NATAL

5.2.1 THE NOTION OF NATURAL CAUSES

In regarding nature as a factor in causing diseases and abnormalities, Zulu speaking-people see natural forces operating on different levels. Ngubane (1977, p. 23) describes two categories. The first deals with the symptoms and the body itself, while the other looks at the role of the environment. After reviewing my data I would like to add three further categories - family relations, sexual habits and a biomedical explanation. The interpretation can shift from one category to another, if the first explanation no longer seems appropriate. Important for people in KwaZulu-Natal is however always to treat the symptoms as well as to understand why a person is affected by a certain abnormality at a particular time. Treatment of body and soul go hand in hand and are seen as a unit not juxtaposed to each other. The five categories of natural diseases will be described below.

1. ´Umkhuhlane´ - Diseases of general character

Maybe I should have known at that time what is measles, because I'm telling you thousands, millions of women like me who have children today, they don't know how much damage the measles can do to a child. Because they never experience it. They just think it happens and goes away by itself. And they don't know, even I today don't know what are the measles. I just know it is a disease that can cause a person to be disabled. (Interview 2, mother of child with severe learning difficulties)

Most diseases in this category are referred to as "umkhuhlane". This term means an "illness that just happens" ranging from serious epidemics like pocks to common colds. Ngubane explains that "Zulus believe that what is natural and alive also ages and dies and therefore has an inherent quality of breaking down". Malfunctioning of certain organs, like an excessive accumulation of the bile (inyongo), can disturb the whole system and cause headaches and debility (Ngubane 1977, p. 23). Diseases in this category are seldom associated with disability and if a young person does not fully recover from such diseases then other powers like witchcraft are believed to have played a role.

Often diseases in this category are also associated with seasonal changes and stages of growth in infants (i.e. measles and mumps) and are seen as being contagious. Concepts are often so general that hardly any explanation is given. Some people seem to also transfer the concept of contagiousness on to disabilities and are afraid of the possibility of becoming infected with the disorder themselves. It is amazing that even staff that work in the department of health can have these misconceptions.

Health services, some people think it is infectious to play with people who are having disabilities, especially people who are working in the department of health. Sometimes some of them think you are going to infect them with what you have. That is some kind of a myth some of the people are having. (Interview 16, man with albino condition)

Should such a disease end in a fatality or cause a disability then other influences are thought to have played a role. In the case of the mother with the measles infected child she was able to gain support as long as the child was in hospital. At this stage the disease was interpreted as being of a general nature. However as soon as she left the hospital and the permanent character of the disability became evident, then the father and his family rejected both the mother and the baby. During the interview it became apparent that the family had now explained the disability as a family related problem on the mother's side, called ufuzo.

2. ´ufuzo´- Family related explanations

My parents they have no problem, they submit to my kid, they take care nicely, but my other parents especially my father in law, they are talking a lot, lot, lot, they are asking questions like: … Since I have been here I had no disabilities here. This is the first time. Now you tell me the truth about this child…, this child where have you got it from?… Now … the father in law took the lobola, just because the child did not talk, she did not do the normal things. He said: Now this is not our child, now I am going to your home to take the lobola back. (Interview 5, mother of severely disabled child)

One of the most common interpretations of mental and physical disabilities is ´ufuzo´. A disability that is obvious from birth on or has been acquired shortly after is said to be inherited. In most cases the father, or his family, will reject the child with the explanation that the child must be from another man, as they have no family members with disabilities. As a result the mother and child can be rejected and sent

back to live with the mother's family. In the case of a married couple the lobola, the African bridal money, could even be claimed back (Interview 5, see above).

The notion of ufuzo also causes many problems for people with disabilities as they are often not believed to be capable of having healthy children. A notion that is also common in Europe and America (Seymour 1998). This however makes it very difficult for people with disabilities to find a permanent partner to live with. As a result they are often denied the opportunity to develop a stable, long term relationship. To illustrate this I would like to end this section with a quotation from one of my interview partners who put all his frustration right in front of me and asked:

Would you go with a disabled man? No, no one wants to be together with a disabled person. We are not attractive and we do not get healthy children. Only if you have money it will change. But then this is not the true love. They only love you for the money." (Interview 9, man with spinal injury)

3. ´imihkondo´- Environmental causes

I think the English word is track or trail. Imikhondo is something that is placed on your track. It could be your driveway, gate door or path to your hut. It can make you feel very tired and weak. You can get swollen legs with all sorts of complications even a stroke or death. If it has happened to you, you can call a traditional healer (Nyanga). (Interview 20, traditional healer)

Many miscarriages, stillbirths and infantile abnormalities are associated with the undesirable elements in the environment usually contracted by a pregnant mother and then affecting the baby. Certain animals, especially wild animals, are believed to leave dangerous tracks, "Imikondo". They can be left on the floor or in the air. Often these tracks are associated with witchcraft and someone that had purposely planted a substance in a person's pathway so as to ill treat them. These tracks are usually invisible and one can contract a disease or disability by accidentally stepping over or inhaling them. Disabilities that are associated with environmental dangers are therefore often identified by their cause, which is usually a mystery, rather than by the symptoms. In the example from the previous section the grandfather of the disabled child could only accept the child through the explanation of a terrible accident. He believed that the mother had stepped over dangerous "imikhondo" during her pregnancy. This African explanation leaves the grandfather the option of

sacrificing to the ancestors and asking for their protection and help. The ancestors are believed to have the power to intervene directly and also to protect them from misfortune. If the imikhondo is caused by witchcraft, a sangoma can give the affected person something that they can use to protect their home. Whoever practices the witchcraft can then suffer from the consequences of their own evil doings (Interview 20).

Some people are considered to be much more vulnerable to environmental dangers than others. Infants and polluted people are believed to be especially vulnerable. They, and in the case of an unborn the mother, must be especially protected so as to minimize their contact with imikhondo. Traditionally a woman will go back to her mother's home when she is six months pregnant. After birth the father is not allowed to come and see the child and if he does, he is only allowed to "stand in the doorway" (Interview 3). In this way he cannot carry any imikhondo to neither the child nor the mother and by the same token the mother's ritual pollution can not become dangerous to him. It is important to note that human beings can be carriers of track components. The "carrier" does not have to be affected themselves as they might be protected well enough. As it is later shown, the system of balance, protection and vulnerability plays a major role in the notion of diseases and disability.

4. Moral and sexual causes

Many of the diseases that are known are actually sexually transmitted diseases. I have a wife and I am working in Jo-burg as a miner. I will leave my wife in Durban for three, four, five or how many years okay. What happens is that other people who are not working might get into nonsense with my wife so it is possible for me as the husband of the wife to do something on her so that whoever she comes into contact with will have a big problem. A lot of things on that one. People actually die on having sex with someone else's wife. That one is the big one. There are a lot of things that happen to you. (Interview 9, man with spinal injuries)

Traditionally the union of the sexes is seen as something natural and good and associated with human fertility (Schapera 1946, p. 108). Sex is, however, also looked at as something unclean and dangerous and consequently as a source of misfortune. People choose to rather not talk about sexual things and as a result there are many myths around the subject. People believe that they can influence their partner's sexual habits through drinking umuthi themselves. They could also give their partners love medicine or secretly leave a substance on their genitals so as to severely punish

their rivals or even, as the above extract shows, cause death. The umuthi used for such purposes can only be bought through a traditional healer or herbalist as they are believed to be able to deal with “African problems and diseases”. The border between natural umuthi and its combination with sorcery is blurred.

Zulu speaking people distinguish between “General” and “African” diseases. A disease or disability believed to be caused through an “African umuthi” can therefore not be healed by practitioners that are said to use only the so-called western methods. This concept is deeply embedded in the Zulu culture, regardless of the person’s educational background. For instance, one participant, who was a science teacher, went to Hospital to visit his HIV-positive brother. In the same room was a man with a swollen scrotum, which he believed to be caused by an African problem. He therefore concluded that the man had made a mistake by coming to the hospital and said “he should have gone to a traditional healer who understands these things better” (Interview 6). In this instance the participant believed that the disease was caused by the so-called “love medicine.” Generally speaking there is a notion that a man suffering from sexually transmitted diseases caused through “love medicine” needs purification known as cleansing. Purification or cleansing rituals differ in a wide range from masturbation, taking umuthi to intercourse with a virgin child (Leclerc - Madlala 1999, p. 207).

Adultery and moral misconduct is not only believed to cause disease and death. It can also cause permanent damage and disability to children. This is only believed possible if one has lost the protection of the ancestors, who probably do not approve with the morally loose behaviour of their descendants. Ngubane reports a case where a young man, who had been adopted, married and took his “genitor´s” name. This was done against the advice of his relatives, “who pointed out that one does not simply change one’s name without including the ancestors in the process. He soon experienced a number of misfortunes. His first child died. His second child suffered from a disease that makes him unable to use his lower limbs, he is partially paralysed …” The father himself became ill with swollen feet and died at the young age of 32. Both his and his children’s misfortune were associated with lack of ancestral protection (Ngubane 1977, p. 48). In this case things could only have been put right again, if the man would have consulted his ancestors with the appropriate rituals.

This example serves to clearly show how interlinked medical concepts can be. The relatives of the man accepted the fact that the misfortunes were caused by biomedical means but believed that this was only possible because he had lost the protection of the ancestors through his moral misconduct.

In other cases abnormal body functions, which are linked to moral misconduct, are believed to be reversible. One participant explained that if a child is born normal and after two years becomes blind this could be caused by the mother not telling the truth about the child's father. Family members will "persuade the mother to tell the truth" and the mother will "feel guilty and confess" (Interview 1). Depending on the interpretation of the disability, the choice of treatment will differ. It is important to note that if a disability is believed to be caused by the mother having lied about the real father, people will no longer feel the necessity to consult a biomedical doctor. Up until the mother's confession, the child will be seen as a shame and be treated accordingly. This is however different if the cause of a disability or disease is believed to be a result of moral misconduct that has upset the ancestors. A traditional ritual combined with a treatment, which can also be of biomedical origin, will then suffice. It is however also possible that the blindness is interpreted as a combination of facts. For instance, the initial lie about the father causes not only the blindness, but also the loss of protection from the ancestors. The mother would then be asked to confess as to the name of the real father, conduct a ritual to the ancestors and take the child to a herbalist or biomedical doctor.

5. Modern science and biomedical models

We can say it is a genetic disorder. Where the particular genes do not become able to produce the white colour and then that affects the skin, the skin and the eyes. That is the only thing that is affected in the whole body. With the mental structures it is really not affected, not unless if it was going to be affected even if you are a different colour. Those genes that fail to give a brown colour or a white colour they give this colour which we call it an albinism condition. It is so sensitive to the sun but it is manageable. (Interview 4, man with spinal injury)

An increasing number of people are exposed to biomedical models and explanations about diseases and disabilities. This is often based on knowledge acquired through formal education. It is therefore not surprising that this knowledge is taken into account, when people explain the cause of disability. Words that have their origin in

anatomical and physiological studies, like “genes”, “spine” and “brain damage” are used to explain the cause of disability. People that use these kinds of explanations will consult a formally educated doctor or practitioner, if they conclude the problem belongs in this area of expertise. Usually these doctors are said to use western types of medicine.

People who only use the ´western kind of treatment´ seldom ask the ´why question´. As a result there seems to be less shame and stigma attached to disability and people can move more confidently in public. In the above mentioned albinism case, the person was not hidden at home. This was however typical for his area in an attempt to protect the “white person” and the “luck” that was associated with them[19]. If people choose to follow the biomedical model then a treatment with protective creams would be prescribed or bought at a local chemist. The person will be seen as being ´normal´ and the disability as “manageable”. It will not then be necessary to perform any rituals. The biomedical concepts are however not always properly understood. One participant who was shot during a raid in the apartheid era explained his story to me. He remembered that he was paralysed as a result of the shooting but claimed that his spine was not injured. As the participant had only sketchy anatomical knowledge, he could explain the disability as having “weak legs” (Interview 16). Even though he tried to explain his injuries in a biomedical context, he did not fully understand the connection between paralysis and spinal injuries.

Most people that explain their disability using the biomedical model are depending on their practitioner’s opinion and abilities to explain the disability, which is very similar to people in Europe (Interview 3).

Diseases and disabilities that are believed to have a natural cause are usually treated with medicine that is thought to be potent and effective in itself. There therefore exists a readiness to experiment and also use the so-called western type of medicine. People do not have to have a biomedical understanding of diseases and disability to choose biomedical treatment. In the African mind it is possible to combine the “western type of medicine” with rituals that have their origin in African

[19] Zulu speaking people believe that people with albino conditions bring luck and therefore need to be especially protected from the greedy eyes of the public. On the contrary, Xhosas, who live predominately in the bordering province, believe that albinism will bring bad luck.

tradition. This is similar to the combination of spiritual and medical based treatment that some people choose in Europe. In the African context the identified natural cause of the 'problem' is crucial. The combination of biomedical and traditional treatment could be used as a possible method particularly when increased vulnerability is suspected.

5.2.2 THE CONCEPTS OF PROTECTION AND VULNERABILITY

For Zulu speaking people the source of good health is not only a healthy body, but also about being in balance with everything around them. This balance is crucial in their concepts concerning health matters. The notion of one's surrounding includes the world one lives in as well as the world of the dead. Balance is created through taking preventive, strengthening medicine and through rituals that keep the person in touch with the ´spiritual world of the dead´.

Some people are considered much more vulnerable than others. Ngubane (1977, p. 28) lists people that are considered to be especially vulnerable as: infants, strangers, people who have had a long stretch of time elapse between preventative treatments, and also people who are considered to be polluted. All these people are considered to be weak and vulnerable. They therefore can easily become victims of misfortune and diseases that are of a natural or supernatural cause (compare to figure 5.5).

People can become vulnerable in three ways. They are either newborns and therefore not as yet in balance with the environment, or they are people who are believed to be polluted, or to have lost the protection of their ancestors.

1. "The ancestors are throwing me away[20]" - Lost protection from the ancestors

You know, in the Zulu culture they believe that the mother and the father, they go and speak to god. They protect you, so you must also honour them. If you do not sometimes the bad luck comes to you. Like you get a child with a disability or HIV/AIDS. You know, because you don't have their protection anymore. Then lets say there is a witch doctor in the street and he does all those things to people that are affected. There are other people that are not affected. It is because these people are protected and you don't have protection. (Interview 9, man with spinal injury)

[20] Quotation from Interview 9

Death and birth are special to Zulu-speaking people and will be accompanied with appropriate rituals. People will undergo a mourning period for a dead person or “isithunzi”. After that there will be a sacrificial ceremony that enables the dead person to take their place under the ancestral spirits or “amadlozi”. Another word used is “abaphansi”, which means “those who live down below” as the spirits of the dead are believed to live below the earth. These spirits are responsible for protecting and disciplining their descendants. People distinguish between ancestors who can punish, reward and those who are powerless. A person’s parents and grandparents are the most important ancestors followed by the father’s brothers. These are patrilineal ancestors to whom a family makes most of their sacrifices. Non effective ancestors are those three generations or more removed from the person and people do not usually perform sacrifices for them.

Each child is placed under the protection of the ancestors by means of either a sacrificial goat or cow. Each family member should be released to the “world below” after a mourning period and sacrificial ceremony. If the person that died is the head of the house then a cow will need to be sacrificed. This is needed so as to please the relative, so that he will use his spiritual powers to protect the living. Ancestral spirits are believed to still have their human characteristics and can therefore be both vain and / or angry. Usually it is believed that this occurs if rituals are not followed accordingly. Ancestors can then lose interest in their descendants who then in turn lose their protection and become vulnerable to diseases and disabilities as well as other misfortune.

If a disability is believed to be caused in connection with lost protection from the ancestors, then the family has the option to sacrifice to the ancestors (Interview 9). It is hoped that the disability will be corrected afterwards. For many people this is an acceptable option, even if the ancestors do not use their influence to reverse the disability. It is believed that the ritual brings the family back into balance with the “other world”, pleases the ancestors and therefore insures protection in the future.

This is especially important for the relatives as it seems to be a way of finding peace and enables them to accept the disability. Feelings of guilt can also be dealt with in this way. The parents do not have to feel guilty anymore because they have made

peace with the ancestors. A typical example of this is the previously discussed case of the mother with her disabled child, who was rejected by the family in-law and accused of adultery. As a consequence of the "ufuzo" accusations the "lobola" was demanded back. Only after the father's family had changed their interpretation of the disability was the mother forgiven. The explanation that the mother had stepped over a dangerous track "imikhondo", while the ancestors had not protected the unborn, was much more acceptable and several rituals with sacrifices were held. Even though the disability of the child had not changed the family could live peacefully together again and the mistrust and accusations seemed to have disappeared.

2. ´umnyama´ - the concept of pollution

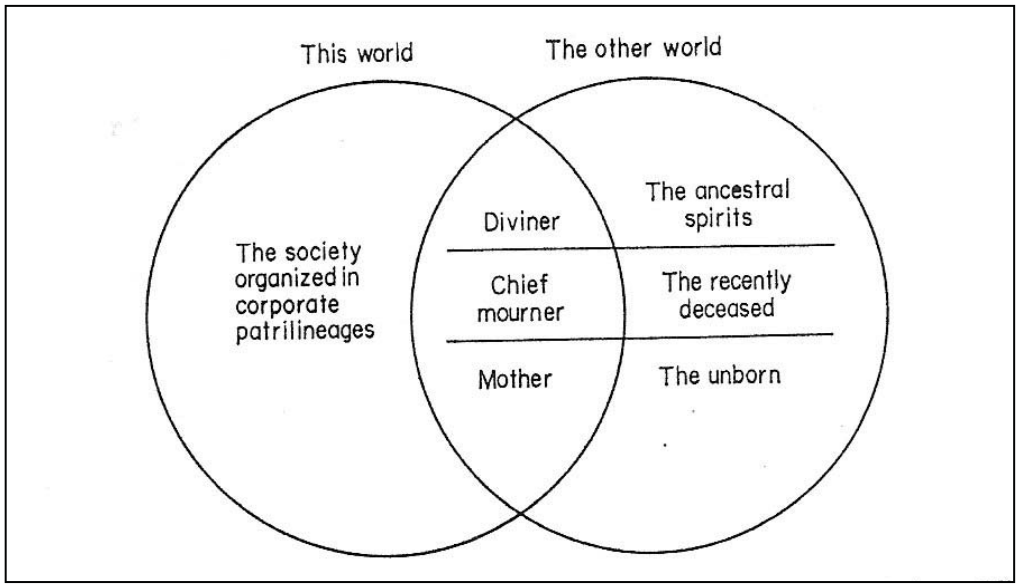
This is called "Intelezi". This medicine we use to clean ourselves. Like, when someone you loved is passed away then he is still with you and this is polluting you. This makes you vulnerable. So you need to clean yourselves of that person. In this mixture is ngamathi and umaphipha. You boil it in water and then you drink a lot of this water, so much until you are vomiting. Then the spirits will go away and leave you alone. (Interview 1, woman with hemiplegia)

"Umnyama", literally meaning darkness, is for Zulu-speaking people a mystical force which diminishes resistance to disease and increases the probability of misfortune. It is often associated with birth and death. The scientific world knows ´umnyama´ as ritual pollution. Often pollution is closely associated with women, because they are seen as a medium that connects "this world" with the "world of the dead". People that are believed to be in touch with the "other world" are considered as being either too strong or too weak, excessively clean or excessively dirty. Diviners or spiritual healers are regarded as excessively clean and strong people, who can get into contact with the other world and ask the ancestors for help. A newly delivered mother and a chief mourner[21] are regarded as being weak and dirty. They deliver spirits from one world into the other and are therefore regarded as polluted. (see feature 5.6).

A "murderer"; "bereaved people" and sometimes people after sexual intercourse are also considered as polluted, but to a lesser degree (Ngubane 1977, p. 89). Different rituals, umuthi or sacrifices can be used to "clean" these people from their pollution.

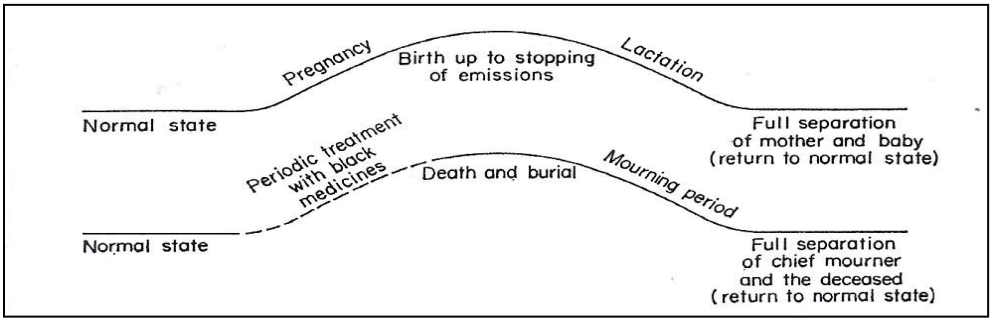
[21] A chief mourner is a woman who is staying with a recently deceased for a couple of days before the body gets buried. The woman is usually the next of kin.

Polluted people are however considered to be out of balance and therefore weak and dangerous. This type of pollution makes you vulnerable and exposes you to diseases and disabilities, if precautions are not taken.



Feature 5-6 The overlapping of "this world" and "the other world" (Ngubane 1977, p. 89)

Of the ´umnyama´ associated with reproductive situations the most common one is the one of a newly delivered mother. She is considered as being dangerous to herself and others, particular the baby and males. The mother's degree of pollution differs at times during her reproductive cycle. Because the mother is regarded as polluted until she stops lactating, she is vulnerable and dangerous to others including her infant. Infantile death is therefore often explained with pollution. The birth of a disabled child can also be explained in this way. The mother and her family are then thought to have not taken enough precaution during pregnancy. Especially in the last term of pregnancy, a woman's resistance to dangerous influences is seen as being very low as a result of pollution (see feature 5.7).



Feature 5-7 Intensity of pollution (Ngubane 1977, p. 87)

The necessary precautions during this time can differ and were evaluated by one particular participant as “good and bad cultures”. As good she interpreted the protection from “stress”, while she thought that the restriction not to eat certain “types of food” like “eggs” was a bad culture (Interview 1).

In the case of a disability, pollution is only able to explain the “why me” question. The treatment will differ in relation to the nature of the original cause. In other words, the treatment will be different if natural e.g. “imikhondo” or supernatural e.g. “ubuthakathi” causes are believed to be the reason for the misfortune.

Notions about blood are widely spread in the world. Human blood is in most cultures a special liquid that needs explaining in one way or another. It is a vital liquid that circulates in the body and appears from time to time at the surface when injured, during menstruation or child birth and in some cases of illness. The mystic element around blood provides the basis for Social Representations on a variety of social and medical phenomena. In her cross-cultural study, Helman (1994, p. 32), identified nine clusters of meanings associated with blood as: “an index of emotional state (blushing or pallor), personal type (´hot blooded´, ´cold blooded´), illness (flushed, or feverish), kinship (´blood is thicker than water´), social relationships (´bad blood between us´), physical injury (bleeding, bruisers), gender (menstruation), danger (menstrual or postpartum blood) and diet (´thin blood´ from bad diet).” For the explanation of vulnerability the relationship between menstruating and danger is especially relevant. In a study conducted by Snow and Johnson low income women in Michigan (USA) were found to attribute menstruation with a purification process. Contrary to that, women in KwaZulu-Natal are seen as partially polluted and dirty during menstruation. This pollution is seen as contagious which is dangerous to the natural world as well as other humans and here, particularly cows and men. It is believed that men’s virility may weaken especially when they would have sex with a menstruating woman.

Because a man can not necessarily know when a woman is menstruating, certain habits have developed in the attempt to protect males from the ´umnyama´ of woman. A man will, for instance, not allow a woman to step over his legs while he is sitting as it is feared that the woman’s ´umnyama´ could affect him.

In some cases the natural wetness of a woman will also be interpreted as dirty. Referring to this notion Leclerc-Madlala (1999, p. 121) presses the point that there exists a "deep seated notion" that women are at all times fundamentally dirty and dangerous and are therefore often seen as the cause of misfortunes such as a child's poor performance at school, extramarital affairs, divorces and even bad weather, drought and heavy rains or flooding. She therefore argues that women are made responsible for spreading HIV and this in turn increases the anger that infected men have towards women. The notion of women being responsible for the spread of HIV has had dramatic consequences for people living in and around Durban. It was only a couple of years ago when a gang of young men were raping and terrorising women in the area of Umlazi[22]. It was an attempt at revenge in which they tried to deliberately infect women with HIV, because they were the ones that had given it to them (Leclerc - Madlala 1997, p. 364).

This fear of pollution through women is still deeply imbedded in the Zulu speaking culture. This is further emphasized by the following statement by one of the participants, who tried to explain why women are so dangerous.

In fact being a male sometimes ladies are usually a threat, a fall down. Especially these days if you go for this one it means that you usually take a spade and dig your grave. (Interview 17, man with cerebral palsy)

The fear of HIV/AIDS has also increased the demand for clean and pure young women. A woman should ideally be a virgin with a tight, dry vagina. Having sexual intercourse with these kinds of young girls is also seen as having a cleansing affect. The other result of this cultural ideal is however that young girls and women with disabilities are increasingly becoming the victims of rape, while other women will try and keep their genital area artificially dry and tight so as to give their partners the illusion of virginity. Both habits result in increasing the risk of HIV infections and this will be further explained in chapter 6.

[22] Umlazi is a district in Durban.

5.2.3 THE NOTION OF SPIRITUAL CAUSES

Whenever a misfortune cannot be explained with a natural cause, supernatural powers are believed to play a role. People have different imaginations about these supernatural powers. In the traditional African belief system, supernatural causes are either sorcery or evil spirits. Most Africans will refer to these types of problems as being of a spiritual kind and African in nature.

The cultural mix with Christianity and Islam has also added God, as a supreme being, to this list. This was probably incorporated into the African belief system without hesitation as the imagination of one Supreme Being already existed before Christianity.

Although not often mentioned, the ancestors can also be a cause of some people's disabilities. This is however not the most common explanation, as ancestors are usually responsible for protection. People that have lost the protection from their ancestors, have failed to take prophylactic ´umuthi´ or are polluted, are seen as not having sufficient immunity or strength to combat against the harming influence of the supernatural powers. The following section will reflect on these notions.

1. ´Ubuthakathi´ - sorcery and witchcraft

In some areas if the child is disabled they are just thinking of a umuthi thing, ja witchcraft. Although maybe the child is affected with polio they won't take the child straight to the hospital they will send the child to inyanga. At the end of the day that particular person will be destroyed because the aid that was supposed to be given while he was still young didn't take place. Like myself. I am from a big family so in a big family there is that jealousy thing. They say your mother has two boys now so one of them must die at least so there was that tendency. (Interview 17, man with cerebral palsy)

The notion that human beings can absorb dangerous elements from their surroundings, provides an opening for sorcery and witchcraft known as "ubuthakathi". Sorcerers, who are usually men, have certain skills and deliberately place harmful substances or use spiritual powers to harm people. Witches are usually believed to be women who use substances to harm people. They can plant a substance at a certain point where the victim is expected to be, initiate a ritual at the time of

misfortune or use a persons “body dirt”, in some cases even parts of the body, to produce a substance that will harm a particular person. A person that is not sufficiently ´immunised´ or strengthened will then fall ill. Referring to this phenomenon, Jewkes (Jewkes & Wood 1999, p. 165) presses the point that the concepts of pollution and sorcery are not causal categories and that they rather form part of a complex interrelationship. Practically speaking, one is more likely to be a victim of sorcery if one is polluted.

The above extract refers to problems found in family relationships. Jealousy is generally thought to be a huge cause of trouble. Rivalling women are thought to be jealous and it is insinuated that they have bad intentions. This rivalry comes from when men had more than one woman, who then “fought” between each other about their rank and influence in the family. If a woman had children, especially boys, then this would increase her status within the family. It is therefore easily assumed that a woman would use dangerous substances to harm her rival. In the above example the aunt was accused of having used umuthi which caused the disability of the participant. Ngubane (1977, p. 35) describes this kind of witchcraft as day sorcery. Most of the time women are suspected of having used this kind of sorcery. Many people believe that a hospital cannot cope with these sorts of diseases and disabilities and will therefore choose to consult a traditional healer.

Ngubane (1977, p. 31) also mentions night sorcery as another type of sorcery that only men use. These men are always using medicine and they are thought to have some superhuman power, like being in two places at one time. It is said that they use “body dirt” like finger nails or sperm to create a substance that can harm a certain individual only. As one participant described, such substances can either be placed in a person’s food or the person is harmed as the substance is being produced, even though he or she might be far away. Madness, insanity and strokes are all believed to be the result of such causes (Interview 8).

Often sorcery is combined with the appearance of an animal. As certain animals are regarded as being messengers from a sorcerer or witch their appearance makes people suspicious of ubuthakathi. Sometimes this suspicion leads people to find the protagonist. One participant shared the cause for his loss of eyesight with me and

explained that it was connected to him having suddenly fallen unconscious, while playing with his cousin outside. Just before the incident the participant, who was then only a child, shouted that "there was an animal coming for him". This indicated to the other family members that witchcraft must have been used and they questioned the second boy for a long time. The latter then confessed that he had been given a bottle by his grandmother and that he was supposed to give this mixture to the child. As the family had a bad relationship with the grandmother she was easily convicted of the misfortune (Interview 6). Because a family member, in this case the grandmother, was involved in the sorcery, it puts this case very close to another type of sorcery that is referred to as lineage sorcery (Ngubane 1977, p. 36). This is a special kind of sorcery where relatives work against each other and try to persuade the ancestors to work in their favour and to ill treat other relatives.

Sorcery gives people a reasonable explanation as to why certain types of illnesses or disabilities are a mystery to us and not reversible with medicine that is classified as being of ´western´ type. This also explains why people particularly visit sangomas for treatments of infertility, mental illness and epilepsy. These medical conditions are not reversible so people look for another explanation (Nattrass 2005b). Sorcery and witchcraft are believed to be African problems and therefore they are to be treated by traditional healers. The grief will however only be aimed at the sorcerer, while the affected person and his/her parents will not be held responsible. Whoever gets identified as the sorcerer will have to be careful, as people do still go out on witch hunts (see appendix 14: The Mercury 29.07.2005).

2. ´Indiki´ and ´iziswe´ - evil spirits

This one here is called "Izinyamazana". I use it to chase away evil spirits. For instance when a child cries at night we will treat it with this medicine. It is made out of dried animals like ngowaya, skhava, imvukuzane, myuan and so on. We will burn this ´umuthi´ in the child's room at night so it inhales the substances and this chases the evil spirits away. (Interview 20, traditional healer)

To understand spiritual possession it is necessary to reconsider the notions about the supernatural world. The already mentioned "World underneath" is thought to be divided into three sections, the unborn spirits, the recently deceased spirits for whom sacrifices are still necessary and the ancestors. Soon after a person dies the spirit is

thought to be in an “in-between state”. It will only be able to take its place with the ancestors after an appropriate sacrifice has been made. If this is not done, the spirit of the deceased is said to become an “indiki”, a restless spirit that can take possession of a person. Epilepsy, mental illnesses or disabilities and suicide are often believed to be caused by these spirits.

Ngubane (1977, p. 142) presses the point that these kinds of possessions are relatively new to the African culture and have developed along with the migrant worker system. Many South Africans die at their place of work and their families do not always know about their death. They therefore do not perform the necessary rituals, which then leaves these spirits restless and in search of their place. It is at this point that they will accidentally enter a living person’s body.

In such a case, people might first consult a traditional healer, and it is most likely to be the ´common´ herbalist. His procedure for a “mentally ill person” was described to me in the following way. The herbalist will use a plant called ´imfamban´, while interviewing the person. He will move the plant around the person during the interview and assess what happens. If “the person becomes worse or even wild and screams he knows the problem is of a spiritual nature” also called “izizwe” and “has something to do with the ancestors”. He will then use a treatment called “inganbazani”, which is made out of wild animals. The ancestors may also have to be asked for help and be pleased with a sacrifice. If the person does not improve after this treatment he sends him or her to the spiritual healer or sangoma. If the person calms down during the assessment period with the plant “imfamban” he knows the problem is “imimoya” and related to evil spirits that have been sent by someone. He would then have to “send the person straight to a sangoma” (Interview 20).

A common phenomenon is the belief in the “Tikoloshe”. This is supposed to be a little man that only comes to children. It is said to affect children that talk with an invisible person. Evil in nature it can even poison children (Interview 20). A child suffering from this has to be sent to a spiritual healer.

Another type of spirit that is a result of sorcery is usually called “iziswe” and it is believed that a sorcerer has caught the spirit and controls it. Often suicide will be explained through the influence of these kinds of spirits.

Africans are very afraid of these types of spiritual possessions and will take as many precautionary measures as possible. People who are thought to be possessed will be rejected and a purification ritual is necessary to bring the person back into balance with the environment. One herbalist explained this in the following way:

You need to clean yourselves of that person. In this mixture is ngamathi and umaphipha. You boil it in water and then you drink a lot of this water, so much until you are vomiting. Then the spirits will go away and leave you alone. (Interview 23, traditional healer)

The special mixture of ngamathi (medicine from a tree) and umaphipha (removed excreta) will only be available through a traditional healer, usually a herbalist. People with mental disabilities and psychiatric disorders are often sent for consultation with a traditional healer. In the case where bewitchment or evil spirits (“ukufa kwabantu”) are suspected to be the cause of the disorder then there will be delays in seeking help from the public mental health care system (Mkize 2002, p. 51).

3. The Supreme Being

Whenever he started crying, my mother used to say `no my daughter you must always think you are special to god` You know, because god left us so many people, who are rich , who can effort, who can give this baby everything, but he has chosen you to have this child. So you must always think that you are special to god. (Interview 2, mother of child with severe learning difficulties)

Shame, she got a curse, maybe she was laughing about people with disabilities, she was laughing at them and this is why she has a baby like this. Maybe she did something, god is cursing her. (Interview 9, CBR consultant)

KwaZulu-Natal has been intensely influenced by Christianity (Leclerc - Madlala 1999, p. 83) and therefore people conceptualise God as being influential when it comes to disability. The notion of god as a supreme being was easily adopted into the African way of thinking, because the traditional Zulu cosmology already included a supreme being uMvelinquangi (the first being) and inkosazane (Princess), who were believed to live “high above” (Callaway 1870, p. 1-5; Krige 1968, p. 180). These old images

are still part of Zulu cosmology in rural areas today and also in agreement with the Christian concept of God. In my first feedback discussion with a DPSA member, who had moved into the city of Durban, she remembered that she used to build a little garden for inkosazane in spring time. This would be done to please the princess and ensure good crops, more cattle and healthy babies. The princess can therefore also be seen as a goddess of fertility and fortune. Other than this uMvelinquangi and inkosazane seem to have very little affect on the day-to-day life and health of people, as traditionally the ancestors are held responsible for this. They are thought to be the messengers between the living and the supreme beings and are therefore more important in Zulu cosmology. Here lies the main difference from the concept of the Supreme Being God, as God does not need ancestors to communicate with the living world, "he" can influence a person's health directly and chooses prophets to send his message to earth.

Depending on the person's point of view a disease or disability will be conceptualised as being a "special task" or a "curse". The notion of the punishing God seems to be widespread and people with disability or their parents therefore often experience stigmatisation. This in return can influence a family in such a way that they will then try to hide the disabled member of their family (Interview 12, 15).

Hiding of people is more common in rural areas, as the chances are higher that the disabled family member stays undetected by other community members. Through a widespread CBR (Community Based Rehabilitation) system, available primary health care (95% coverage in KZN) and government health workers, these cases are becoming more and more rare in the new South Africa. There are however still not enough community workers to eliminate this problem completely. Even if the person with the disability has been identified, it does not mean that he or she will then automatically be able to participate in the community, because the disability will still be seen as a shame. Also parents and family members of disabled people are often worried about their safety. One interview participant, a community worker and occupational therapist, explained that a large number of parents are worried that their disabled children could be abused, while they are absent. As parents in rural areas do not necessarily have someone to watch over their children while they see to other

things, they will lock their children inside their hut. Unfortunately with the open fires inside there have been accidents (Interview 13).

5.2.4 THE SOCIAL CONCEPT OF DISABILITY

For me a disability means there is a lack of access that is because a lot of disabled people are physically challenged. There are limitations, you know. When I think of disabilities, there are many disabilities. There are mental disabilities, there are physical, blind and all those people, if there were opportunities and those were really helping us to overcome our dysfunction, like I have the computer. (Interview 1, manager of DPSA KZN)

In addition to the physical explanation of disability some people and especially people with disability that are organised within self help groups, have developed another way of explaining disability. The social side of the phenomenon of disability will be taken into account and barriers will be explained with a lack of access to aid and with negative attitudes from non-disabled people. As described in chapter 4, the lack of general facilities makes it difficult for people with disabilities to access buildings and facilities, make use of the transport system and communicate with officials. They perceive this as a major barrier and hold it responsible for their exclusion from society. People with disability also experience different attitudes from non-disabled people. They are often seen as being incapable and in need of help. They are also often limited in there decision making and participation in society, as people quickly conclude that because of a certain problem, like for instance blindness, a person is not capable of doing anything and can therefore “not decide” for himself or herself (Interview 16).

In my interviews the problem of attitudes was a re-occurring theme. These negative attitudes can also be described as stigmas. Stigmas are in general understood as an attribute that triggers social discredition (Gill 2001, p. 355). The social implications are the denial of privacy, superficial acceptance and the status of being a non-person. The latter, in particularly, is often experienced in the field of sexuality, where people with disabilities are often pushed aside as asexual and not capable of a relationship.

While rereading my data I was also able to identify Davis’ three stages of overcoming stigma as: fictional acceptance, breaking though and institutionalisation of normalised

relationships (Davis 1961, p. 127). In the first stage, “fictional acceptance”, non-disabled people treat people with disability superficially as equals. This was confirmed by a female participant who described how she was accepted during meetings as a representative for people with disabilities by the local women group, but was excluded from participating as a woman in the same group.

Davis describes the second stage of “breaking through” as the stage when a person with disability discloses sufficient personal information to challenge stereotypes and encourages the non-disabled person to see the affected person as somebody with the same interests and perspectives. I would place most of the better educated participants in this category. The participants described how they looked for “opportunities to overcome their dysfunction” and “approached communities” so the community members would better understand disability. The main barriers to break through were predominantly physical barriers and lack of aid. Disability in this context was seen as “lack of aid”, “limitation”, “meeting barriers” and to be “physically challenged”. Only very few advantaged people in KZN reach the last stage of “normalisation”. Most commonly this depended on financial terms. In my sample I would categorise one businessman, one regional manager and one person that had inherited a sufficient amount of money to be in this group. In their individual experience they would see themselves “as not being disabled”.

Disability organisations like DPSA (Disabled People South Africa) try to make their voice heard and help change living conditions for disabled people. On a national level[23] there is already a shift that recognises disability as a disadvantage. Documents like NIP (The National Integrative Plan) or the Inclusive Education Policy, known as the White Paper, have been written to change attitudes in institutions and overcome barriers. The process is however slow and often necessary aid is lacking, so people still experience great barriers. The manager of DPSA explained that there is a lack of qualified administrative staff on a provincial level, which has led to a general failure to implement policies such as inclusive education. She mentioned that there is also a lack of qualified staff on a local level (e.g. sign interpreters and special educationalists), which leads to poor service delivery (Interview 1).

[23] This could also be seen as the macrocultural level.

In the context of the social model of disability it is interesting that some people with disability criticise their own kind for quickly relying on aid, without any initiative to change their own life. This phenomenon would be summarised as “having attitudes”. One of my participants described his opinion about disabled people in the following way.

Yes the attitude. It is the attitude of blind people. Because what they feel is that they need to be assisted. You understand? And I feel the time has come, when you see a disabled person you need to feel shame about him. They need to wake up and stand up and work, earn their living. Not only to depend on the government hand out grant. So now, firstly when they at the workplace, they need to change that they are disabled, but they need to perform well. Their attitude is that everything, all is going to be given to them. They don’t bring in more ideas. (Interview 7, visually impaired business man)

On the one hand it is interesting to notice that the participant had a visual disability himself and had experienced exclusive education in a school for the blind. He described how that exclusive environment did not help him to develop an understanding of the “world outside” and that during that time he only socialised with blind people. He however changed during his high school years to a mainstream school and found this school much more stimulating and it enabled him to stand his ground after school. Even though he did not manage to finish his Matric year, which was very likely the result of having had a lack of visual aid and special assistance at school, he did manage to become a successful businessman later in life. He himself explains his success by his exposure to mainstream standards and his change of “attitude”.

On the other hand, one must mention that there are enough other examples where children do not manage in a mainstream setting. Mongezi Ngidi (2005, p. 39), in his biography about his albino condition, describes the limiting conditions at a mainstream school. He battled to read and write, as his condition also affected his eyesight. As described his teachers did not pick this up and positioned the “lost child” in the back of the classroom. As a result he failed in a mainstream school and was later sent to a special school. This school then enabled him to develop his skills appropriately and as a result he managed to study at University.

What Ngidi and the above mentioned participant have in common is there self-confidence and positive attitude towards life. This enabled them to identify the social barriers they experienced and as a result they managed to overcome them.

5.3 CONCLUSIONS

Chapter 5 illustrated how notions about the cause of disability emerge and affect the individual experience of disability as well as the way a person and the disability are treated. Depending on the personal relevance and the Subjective Theories a person develops towards a particular condition, abnormality will be either attributed with a natural or spiritual cause or a combination of both. Notions of vulnerability and precautious behaviour influence this explanation as well. People will choose, in accordance with their different practitioners and spiritual leaders, their treatment procedures or will feel no need for intervention. The threshold of perceiving a condition as abnormal and the conceptualising of this abnormality influence the need for intervention. Due to the fact that traditional healers and spiritualist are available even in remote rural areas, people familiar with African custom often choose them as the first specialist to be consulted with in regard to an illness or other problem. Diseases that are thought to be of an African nature, for instance the possession by evil spirits, will most likely be referred to a traditional healer. Based on his or her assessment the healer will either treat the “problem” himself or herself, or refer the “patient” to a clinic or a shaman/sangoma.

On the one hand notions about disability can lead to the rejection, exclusion or mistreatment of disabled people. I therefore want to press the point that the notions about disability do, to an extent, negatively affect the relationships with other people. Depending on how the disability is interpreted, people will be welcomed or refused by their family, will be exposed to the outside world or hidden behind walls and will be overprotected or exposed to abuse. One participant explained the situation in the following context:

People think that these people are not supposed to get married. That is what they believe in. Maybe Africans believe in that because she is disabled she must be kept here and looked after. As a baby it doesn’t matter how old until he is an old man he doesn’t get married. (Interview 15, nurse and sexual educator)

However, as the next chapter will show, people with disabilities are sexually active, regardless of their marital status and sometimes even regardless of their own will. So the overprotection as shown in the above example might prove to be more of a problem than a help.

On the other hand it must also be mentioned that the African medical knowledge can be used to reintegrate excluded people. Due to its holistic approach, traditional healing practices can have a positive affect. As this type of healing involves the unconscious aspects of the mind, the patient can be given the opportunity to express emotions. He also might overcome anxieties through the dramatising effect of rituals or prayers. The notion of ancestral spirits and supernatural beings gives meaning to life. An individual might find comfort in the imagination that life does not end in death. The reinterpretation of disability can lead to a change in attitude and acceptance in a family. Rituals that are thought to please the ancestors also help a family to deal with a misfortune and with that might speed up the process of coping with a disability. The positive interpretation of seeing disability as a task rather than a curse can have a similar effect. Even so it may not always have been used in that sense the African “semantic network” keeps these opportunities open.

In addition to this, there are some very promising examples of people with disabilities who have managed to take control of their own lives and make it a success. All these success stories share an awareness of the social side of disability. The people behind it are empowered and confident people. They were not born like that, but have developed through a process into what they are.

To summarise is to say that the individual conceptualisation of disability can influence people with disability in a positive or negative way. There are some misconceptions that need to be overcome without destroying the ´healing´ potential that African custom can provide. How these positive and negative interpretations of disability and disease effect people with disability in relation to HIV/AIDS will be discussed in the following chapters.

PART III

DISABILITY AND HIV/AIDS IN KWAZULU-NATAL

6. THE CONTEXT OF HIV/AIDS

HIV/AIDS is a very complex phenomenon which can be defined in both a medical and a social dimension. It influences society on different levels, be it the macrocultural, microcultural or individual level (McElroy & Jezewski, 2000, p. 192).

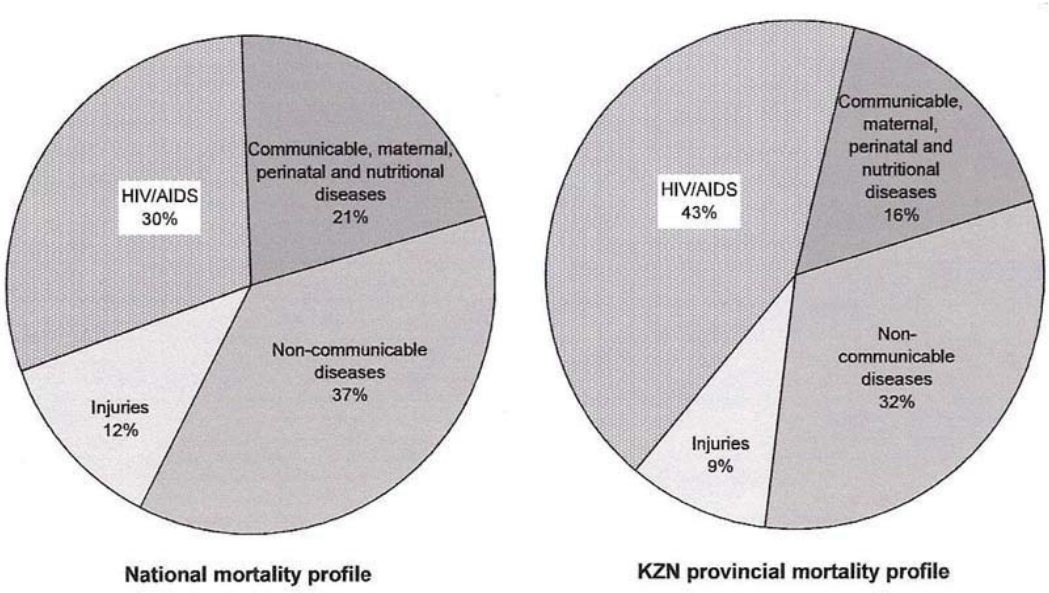
This chapter will therefore look at various areas of society and analyse the effect of the HIV/AIDS epidemic on an individual as well as on a broader level. On a macrocultural level the first part of this chapter will confront the reader with statistics, policy development and the history of HIV/AIDS. The second part of this chapter will take the reader into the microcultural level and focuses in particular on the gendering elements of the pandemic. Finally, the third part focuses more on the individual level and the associated sexual culture. It is important to describe the epidemic in such detail that the reader will be able to position the phenomenon disability within the broader problem of AIDS. Disability in the context of HIV/AIDS will be discussed in chapter seven.

6.1. HIV/AIDS IN SOUTH AFRICA

"The history of AIDS policy in South Africa is a sorry tale of missed opportunities, inadequate analysis, bureaucratic failure and political mismanagement" (Nattrass, 2004, p. 41)

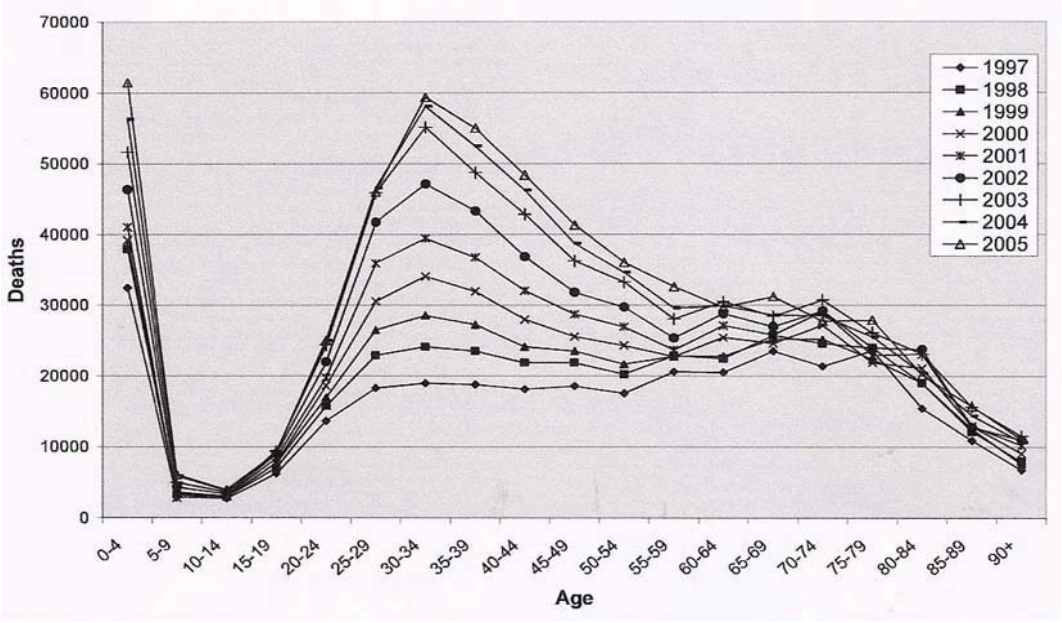
6.1.1 FACTS AND NUMBERS

AIDS has become one of the greatest killers in KwaZulu-Natal and with this it has become a threat to South Africa's economic development as well as its educational and health system. With it still being a taboo, the real AIDS related death rate is difficult to evaluate accurately. The Medical Research Council (MRC) has used the death registration system in South Africa to show which diseases are the biggest burden to the country (Brandshaw et al., 2004). HIV/AIDS was amongst the four major diseases that are also described as a "quadruple burden" to South Africa (see feature 6.1).



Feature 6-1 Estimated mortality rate by disease group in South Africa and KZN (Brandshaw et al., 2004)

The research results from the MRC demonstrated the high proportion of deaths due to HIV/AIDS. Statistics South Africa made another attempt to capture the extent of the epidemic, through an analysis of age-specific death rates (see feature 6.2). The mortality profile should be quite accurate as the death registration process has improved over the years and is estimated to be at about 90 % complete.

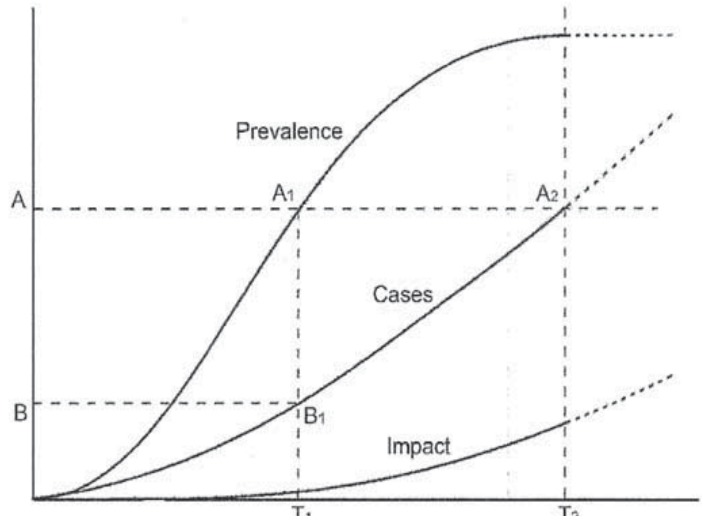


Feature 6-2 Mortality rate by age (StatsSA, 2007)

Examining the graph one can easily detect the problem. South Africa's mortality rate of newborns and infants is far too high for a middle income country, part of which can be attributed to HIV/AIDS. Of even greater concern should be the high mortality rate in the age group of 25 to 45 year olds. These are the people that are very likely to be sexually active but should be naturally strong and have a low mortality rate. The high death rates in this age group can surely be attributed to HIV/AIDS, as other determinants like crime or accidents should affect all age groups in a similar way.

The capturing of prevalence rates has provided researchers with more obstacles and difficulties than the statistical measurement of death rates. Some researchers have used antenatal data, others volunteer testing, to measure the prevalence rates. Others refer to AIDS related diseases but all argue about the real infection rate of HIV. Depending on the sample the prevalence rate can differ between 10% and 41% (see appendix 5, 6, 7). Sometimes even prevalence rates of as high as 70% (The Mercury 7.09.2006) have been quoted and this adds to the confusion of the public. Usually lower prevalence rates are measured within a sample that represents different ages and sexes more realistically. Such samples do however depend on volunteer testing and as HIV/AIDS is still a taboo topic it is likely that infected people might not volunteer for the test. Another way of gathering data is through antenatal testing usually in government hospitals. These samples get much higher prevalence rates. It is argued that antenatal testing is not representative of the population as participants in this sample will be poor to middle income sexually active woman, who do not protect themselves against infection. Confronted with such a variety of results, one can only be sure about the fact that the truth lies somewhere in between and that the prevalence rate is high. Considering the increase in prevalence rates in all studies one has to come to the conclusion that the virus is spreading at a tremendous rate.

The rising HIV prevalence rate is however only considered to be the first wave of the HIV/AIDS epidemic. AIDS deaths and the increased burden for the community while looking after the sick and orphaned are seen as the next waves (see feature 6.3). In general the waves are not easy to position, but various researchers have managed to attach a timeline to the scenario.

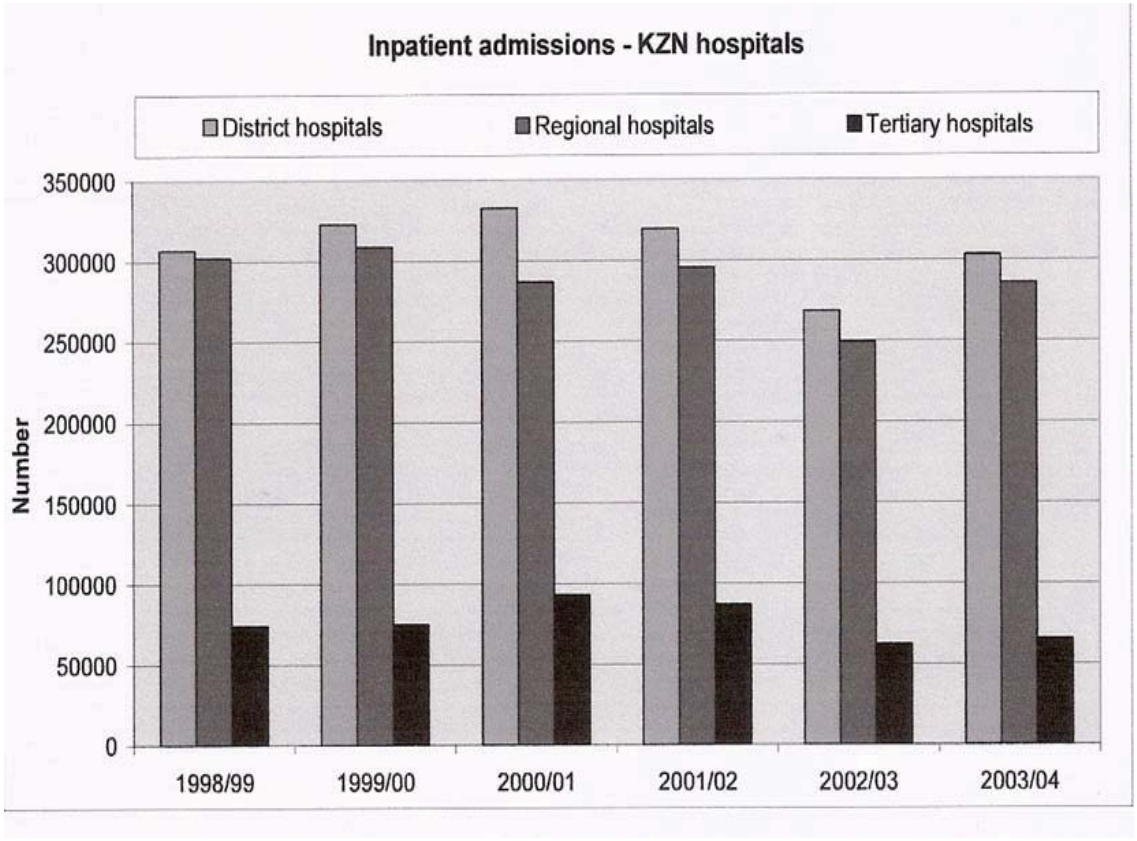


Feature 6-3 The three HIV/AIDS epidemic curves (Barnett et all. 2002)

The first wave is seen to have occurred in the 1990s while the second wave has been placed after the new millennium (Veenstra, 2007, p. 15). Of particular concern for South Africa is the fact that the impact (third wave) of HIV/AIDS on health services and communities has not as yet reached its peak and that further complications can be expected. Looking at South Africa's social development one could almost conclude that a fourth wave could follow or has already begun. This is the wave of skilled emigration combined with an increase in poverty driven crime. This would be of particular concern as it would destroy already fragile social structures, authority and behaviour control mechanisms. In such a climate civil unrest or dictator-leadership styles could become a threat to the young democracy.

HIV/AIDS has presented itself as an unprecedented threat to the development of South Africa. In the face of such terrifying statistical facts, popular opinion is that this has increased the strain on the health and social system. Research (Veenstra, 2007, pp. 18,19) however shows that this is not necessarily the case. It is slowly becoming apparent that health care facilities are not swamped with the burden of providing care (see appendix 8a,b). South Africa is in a similar position to other African countries. The relatively stable bed occupation rates in hospitals (see feature 6.4) have led researchers to believe that hospitals have ´rationed´ care as a coping strategy to avoid overcrowding (Veenstra, 2007). This is a fact that can be supported by comments from my interview partners, who expected HIV patients to get less access

to health services and to be turned away quicker as there “is not much that the hospital can do”. Thus it seems the strain on health service cannot be captured in numbers.



Feature 6-4 Inpatient admission over time (Veenstra, 2007, p. 68)

Why are people not seeking care? Commonly this phenomenon is explained with the public notion that hospitals have little to offer and are expensive (see above). This may be particularly true for HIV/AIDS as it is often interpreted with the influence of sorcery and pollution (refer to chapter 5). A common notion is that a sorcerer can “bewitch” a person and make that person ill. This will be particularly easy for the sorcerer if his victim is not protected (e.g. by the ancestors) or polluted (e.g. through contact with death or a menstruating women). This notion would classify HIV/AIDS as an African disease which would accordingly be treated only by a traditional healer. People therefore would not see the need to refer to a hospital. Other important reasons given for the present care seeking behaviour are that there is still a stigma attached to HIV, negative attitudes by nursing staff and a ´rationing´ attitude to avoid overcrowding in hospitals.

Hospitals have however operated within their capacity. More useful questions are about the quality of service, the notorious understaffing of hospitals and clinics and the access problems for many potential patients. Human resource (HR) management is an ever increasing problem in South Africa and the effects are also known as "brain drain". Post vacancy rates are increasing in the health as well as in the education sector. The increase of workload, insufficient skills and experience as well as psychological stress is being experienced by many staff members in these sectors (Veenstra, 2007, p. 22).

AIDS puts an additional pressure on hospitals and clinics which is not necessarily measurable quantitatively but rather qualitatively. Employees in the health sector are, on the one hand, directly affected through HIV infection[1] and are therefore more often sick or have to retire. On the other hand, working conditions are increasing the strain on the workforce which causes a high attrition rate. Skilled people are either emigrating overseas or into the private sector. As Veenstra (2007, p. 109) discusses in her thesis, HIV/AIDS increases the unfavourable factors for medical staff. She lists four `push factors´ that are influenced by HIV/AIDS:

- poor salaries
- heavy workload
- limited career options
- inappropriate management styles

Poor salaries and an increased workload stand in close relation to each other. The workload has increased through HIV/AIDS, as more medical staff have to take leave while being sick or attending funerals, which leaves the remaining staff under pressure. The lack of success in filling open vacancies, particularly in rural areas, has added to this problem. HIV/AIDS has also directly increased the workload as it added additional work through testing, counselling and treatment. Although HIV patients account for only 12% of admissions, 23% of direct patient care resources were spent on HIV-related illnesses in 2005 (Veenstra, 2007, p. 88). Nurses and doctors in particular feel that what they get paid is not worth all the effort they have to go

[1] Medical staff get infected either through contaminated needles or from having alternative sexual partners while working away from home. There is a public notion that medical staff should know what they are doing and protect themselves. The stigma attached to HIV infection is therefore very high for medical staff.

through. HIV/AIDS can also limit career options, when for instance a doctor would like to specialise in paediatrics but feels in South Africa he would still spend most of his time dealing with HIV. In addition to the hardships of medical staff, management styles in hospitals are often lacking appropriate HR-understanding. Managers, all too often, will only see themselves as administrators and not as responsible for dealing with the 'motivation' of staff or developing staff programmes to assist with workload management or HIV/AIDS related problems (Interview 13). As a result a high number of nurses and doctors are leaving the field. Adding to the problem some medical institutions have issues in employing or working with people of certain race groups, which drives these people out of the profession and they often even end up leaving the country (www.hst.org.za). This could be added as a fifth element to Veenstra's list.

Another obstacle to people seeking care in the public health sector is access. Particularly, the treatment of HIV with Antiretrovirals (ARVs) has begun very late[2] in South Africa due to the dispute about how to deal with AIDS and whether ARVs would poison patients. People therefore have to learn and hear about the option of treatment before they will come and access it. Care seeking could be delayed. In rural areas, but also in townships the access problem might also be of another nature. Many participants in my study, but also in other research, mentioned the fact that transport to particular hospitals is expensive and unaffordable. In addition to this, AIDS patients often have to be accompanied by an additional person as they are too weak to travel on their own. In poor communities this becomes unaffordable and people may therefore not be able to seek care (Interview 18). Another factor is the stigma that is still attached to HIV/AIDS. Due to the stigma, people with HIV might not participate in Volunteer Testing and Counselling (VTC). Ignorant of their status they also do not look for treatment.

HIV/AIDS also has its degrading effects on private households. Already strained through increasing living costs and interest rates, South Africans have to spend more and more of their resources on HIV/AIDS related issues. As a result the individual household has to:

[2] Brazil as the first developing country in the world began its ARV programme in 1996 eight years before South Africa. Although South Africa is catching up with other countries it still makes less ARVs available (in percentage) compared to other countries in Southern Africa (Veenstra, 2007).

- spend more money on medical and funeral costs
- spend less money on food and regular expenditure items
- spend less money on education

As a consequence the poverty gap between rich and poor has widened and more and more people have to be supported by charity and social grants or need to make a living through begging or crime.

South Africa, like Zambia, can be described as a radical reformer of health care (Veenstra, 2007, p. 31). The White Paper and its legal companion the National Health Act (2003), outline a very progressive instrument that attempts to overcome previous inequalities, deliver basic services and decentralise health services. The latter, however, seems rather to be an obstacle in HIV/AIDS treatment. As treatment with ARVs is still a very new approach and requires a certain amount of knowledge and training, nurses at the local level did not necessarily have the required knowledge and skills (Veenstra, 2007). An extensive training phase of clinic staff still needs to be implemented. Up until now ARVs have only been available at the district hospitals.

In general the health sector, although it has had its funds increased in recent years, has had to change its focus from Primary Health Care (PHC) to Selective Primary Health Care (SPHC). SPHC is a more cost effective approach and focuses on the major problems, a trend that has also been adopted on an international level. In this context many local based clinics have been built in recent years[3] and Home Community Based Care (HCBC) has become an important element in the care for AIDS patients (Veenstra, 2007, p. 129). Here, I see an important chance for other community structures like CBR (Community Based Rehabilitation) to be integrated and with this to improve the overall health care for a community.

As mentioned earlier HIV/AIDS is not only a medical phenomenon but also a social construction. The context in which the epidemic unfolds shall therefore be discussed in the next sub-chapter.

[3] KwaZulu-Natal has achieved a tremendous amount in recent years. Left with a very unequal distribution of PHC through the Apartheid system KZN managed to invest in PHC so that it had reached a 95% coverage rate in 2005 (Health Department KZN 2005).

6.1.2 HIV/AIDS DETERMINANTS

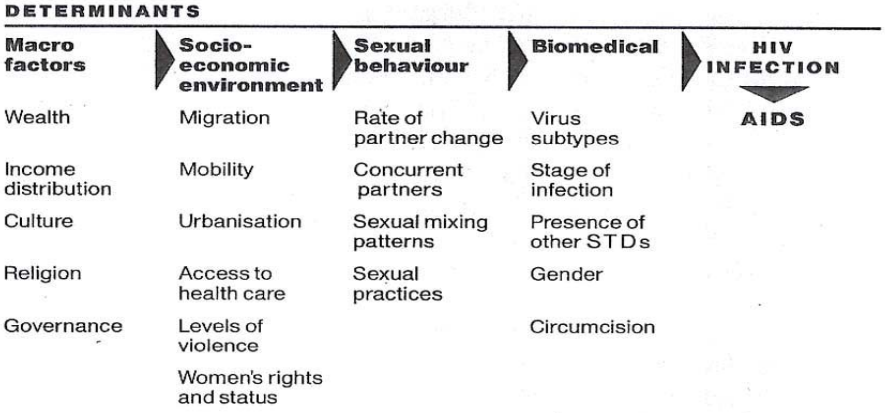
In KwaZulu-Natal most infections are of a heterosexual nature. Even so the epidemic started, like in many other countries, as a “homosexual problem” in the 1980s. In the 1990s heterosexual transmission overtook homosexual transmission very rapidly (Veenstra, 2007, p. 10). At some point there were two different patterns of HIV transmission, one starting earlier than the other. The transmission amongst homosexuals was characterised by the subtype B of the HIV-1 virus, which is the same virus strain that is also commonly found in Europe and North America. The heterosexual transmission was, on the contrary, caused by the subtype C of the HIV-1 virus strain (Whiteside & Sunter, 2000, p. 7). Its origin most likely lies within Africa itself. It is the latter that is of interest here, as most infections now come through heterosexual contact. The high rates of heterosexual transmission are puzzling as the chance of heterosexual infection is relatively low[4] and can therefore not be explained by an abundance of sexual intercourse. Additional conditions must be present in South Africa and particularly KwaZulu-Natal. This shall be presented in the following chapter.

As described earlier, South Africa and especially KwaZulu-Natal has had a turbulent past, with political violence during Shakas regime, colonialism, the apartheid period, factional fighting in the first few years of the new republic, followed thereafter by a high crime rate. This history of crime and violence as well as the segregation policies of the colonial and apartheid eras planted the roots for the quick and immense spread of HIV. I speak here of roots because the violence and exclusive land policy caused the supporting factors for the epidemic to be common in KwaZulu-Natal. Whiteside and Sunter (Whiteside & Sunter, 2000, p. 20) call these factors HIV epidemic-determinants.

These determinants are poverty and the big difference between income groups, a highly mobile population, disrupted family relations, the migrant labour system,

[4] 1-2 woman for every 1000 exposures get infected with the virus, while it is only 0,33-1 of every man, but 130-480 for every child of an infected mother (Whiteside & Sunter, 2000). This data is based on sexual intercourse under normal circumstances, where both sides agree and no STDs are prevalent.

gender imbalance and a general exposure to violence (see feature 6.5). All of these supporting factors can be found in KwaZulu-Natal.



Feature 6-5 HIV epidemic – determinants (Whiteside & Sunter, 2000, p. 20)

As an example the province has the two biggest harbours in southern Afr a and therefore attracts a substantial amount of traffic. The spread of HIV is know to be most pervasive in areas surrounded by heavily travelled roads. High prevalence levels have also been explained through differences in income, education and the different levels of urbanisation all facts that differ enormously in KwaZulu-Natal (Gow & Desmond, 2002, p. 32). It has to be pointed out that even though poverty is believed to be connected to the spread of HIV, it is not necessarily the poorest that suffer the most. In South Africa the emerging middle class seems also to be affected. They have enough money to entertain and sometimes their career puts them in a position of power (policeman, teacher), so access to various kinds of sexual encounters is much easier for them.

KwaZulu-Natal also has a significant amount of migrant workers, who live for long periods far away from home while they are tending to their jobs. This obviously weakens relationships and encourages multiple partnerships, which are also customary to African life. The gender gap in the province is tremendous, especially when it comes to rural areas or poor communities. Women have a lower socio-economic position and "as a result of their financial dependence on their partners they are unable to insist on safer sexual practises" (Gow & Desmond, 2002, p. 28). Although most people have access to basic education; sexual education especially through parents and other educators is only slowly developing. Sex is usually still a taboo topic. The traditional "Sex educators" have disappeared (Harrison, Xaba,

Kunene, & Ntuli, 2001, p. 70) and young people are often left behind without guidance (Leclerc - Madlala, 1999, p. 43).

A theme that is not usually mentioned but emerged in my data, is the theme of "freedom". One participant of my study explained that with the change of the system in 1994, young "black people" did not want to be told anymore what they have to do. They wanted to experience absolute freedom and this also on a sexual level. They wanted to do what they pleased and just "play the field" (Interview 14). This however also meant exploring sexuality in a risky way, which certainly will have contributed to the fast distribution of HIV/AIDS within the younger generation.

6.1.3 A SHORT HISTORY OF HIV/AIDS POLICY MAKING

As varied as the HIV prevalence rates are, as various are the messages about ways of infection and protection. In general the South African government has been quite delayed in dealing with the issues surrounding HIV/AIDS (see appendix 4). Confusing and contradicting messages have been sent to their people and even the link between HIV and AIDS has been denied. Through these policies the lives of many South Africans have been risked and lost (see chapter 6.1.1). It was only at the beginning of 2007 that a change in government attitude started to become apparent and the Deputy Health Minister became more active. At this time the infection had already developed into a full blown epidemic and unfortunately after trying to take 'action', the Deputy Health Minister was removed from her post.

While looking for an answer as to why the South African government has been so slow to respond, one can press the point that this government had to deal with many issues that emerged through the previous inequalities and that they maybe therefore did not prioritise HIV/AIDS on their agenda. Maybe there was also the naive hope that the problem would just disappear. The new South African government has, for quite some time, hung onto the concept that HIV does not cause AIDS. The president Thabo Mbeki himself, and his Minister of Health Tshabalala-Msimang, advised their people in 1999 to "find out where the truth lies" and to consult the "huge volume of literature" (Nattrass, 2005) that was available on the internet. It is more than likely that they referred here to Duesbergs website (www.virusmyth.com). Duesberg's theories that drugs and poverty caused AIDS and not the HIV virus were for a long

time favoured by Mbeki´s government (Cohen, 1994, p. 1642). It was probably also a romantic notion that 'western' drugs and apartheid were to be blamed for AIDS instead of addressing the very complicated subject of sexual culture and its link to HIV. It is also very likely that the leaders of the new republic found it much easier to blame the old enemy instead of addressing the ills within itself.

Up until today, people in South Africa have received very mixed messages about HIV and AIDS. In 2005 the German vitamin entrepreneur Matthias Rath, claimed that he could cure AIDS with his vitamins and that Antiretroviral (ARV) drugs were a form of poisoning (The Mercury, 11.05.2005). The strengthening idea of vitamins fits very nicely into the African notion about diseases (see chapter 5) and he therefore was very successful in distributing his vitamins. Cases became known where people died after they had changed from ARVs to Rath's vitamins. The South African Minister of Health Tshabalala-Msimang, however, refused to distance herself from the vitamin entrepreneur because it could not be demonstrated that the vitamin supplements were poisonous for people infected with HIV (The Mercury 28.06.2005). In fact, Tshabalala-Misimang encouraged people to try out traditional medicine rather than the poisoning ARV´s. The most prominent case is Fana Khaba, a popular Johannesburg DJ who rejected HAART[5]. After he had already undergone several "traditional" treatments and its failure was apparent, the Health Minister phoned Khaba´s mother to tell her that she was sending the Dutch retired nurse Tine van der Maas to help them. His CD4 counts were, by that stage, only two[6] and he was advised to take a nostrum called "African solution". Khaba died three months later at the age of thirty-five his body wasted and in agony (Nattrass, 2005, p. 14). If the Health Minister would have intervened differently the outcome would almost certainly have been different. In her desperate attempt to find an African solution[7] to the HIV/AIDS epidemic, the Health Minister made herself look ridiculous in front of the world. In 2006 the same minister represented South Africa at the International AIDS conference with beetroot and African potatoes as the main tool to fight the epidemic. ARVs were only mentioned on the side. The contradicting effects of both were not

[5] HAART - Highly Active Antiretroviral Therapy
[6] A CD4 count of under 200 qualifies for ARVs.
[7] Associations with the pre-1994 struggle and the modern idea of an ´African Renaissance´ could be responsible for the desperate attempt to find a solution in Africa. These associations talk about the need for an African solution to an African problem rather than to consult the ´old enemy and suppressor´, who is expected to carry on suppressing and undermining the African way of life.

mentioned at all.[8] As a result, 60 international experts on HIV/AIDS called for the resignation of Tshabalala-Msimang after the AIDS Conference (Veenstra, 2007).

It is interesting to note that quite a number of AIDS dissidents who came up with ´African solutions´ can hardly be presented as ´African´ themselves. The German vitamin entrepreneur Matthias Rath, the American scientist Duesberg, the Dutch nurse Tine van der Maas and the Belgian organic farmer Kim Cools have been some of the main advisers to the Health Minister and President Mbeki (Geffen, 2005, p. 186). They can hardly claim to work from a traditional African perspective nor do their products pass any scientific standards. I therefore can only enforce Nattrass' argument that so called "African traditional or alternative healing" outside scientific regulations can only too easily turn into a "Trojan horse" open for all purveyors of unproven substances (Nattrass, 2005, p. 10). In the face of the serious consequences of an HIV infection it is also questionable how important this ´African´ way is for the infected people that must now face premature death. Maybe the desire to find an African solution to AIDS has distracted attention and opportunities have been missed along the way.

6.1.4 MISSED OPPORTUNITIES

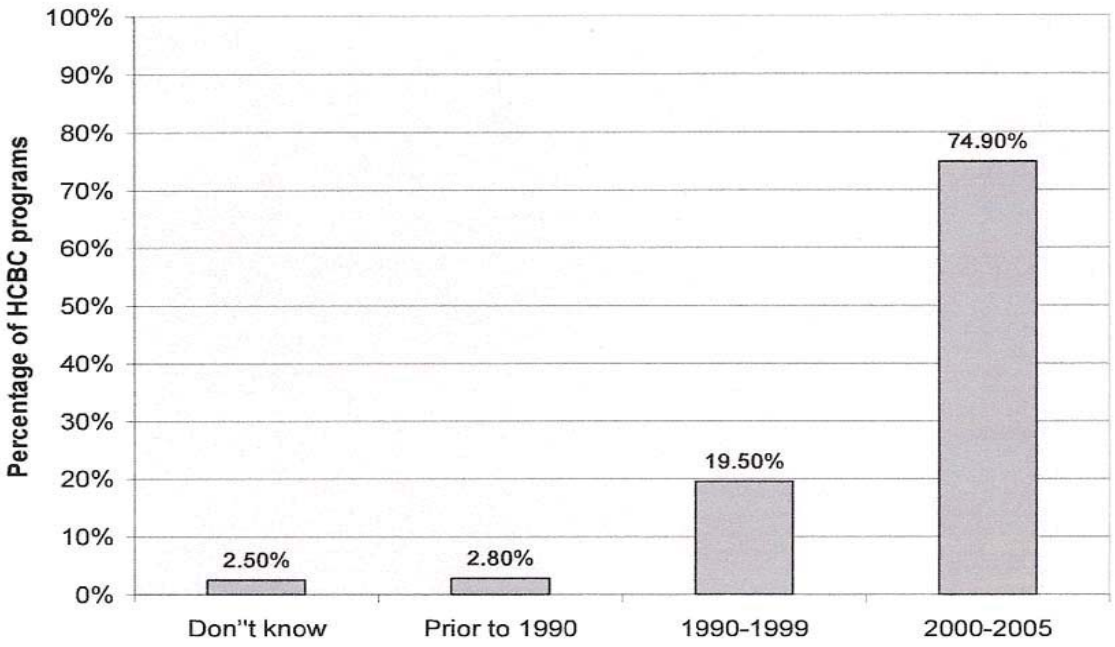
Dr. Kevin De Cook, director of WHO's HIV/AIDS department, highlighted three missed opportunities after the 2006 International AIDS Conference in Toronto and openly criticised the South African government for its response to the HIVAIDS crisis (De Cook, 2006). He pointed out how South Africa could have shown leadership for the African continent, given its economic and political importance. Without its denialism and tactical delaying of actions, the country could have received a tremendous amount of international support for prevention as well as treatment. Success would also have been greater, if the right actions would have been taken earlier.

Instead the late and, as it appears, unwanted[9] change in course, seems to have affected other areas of social society negatively as well. The government's failure to

[8] African potato for instance reduces the effect of ARVs (TAC, 2005)
[9] Antiretrovirals were only made accessible after TAC took the Minister of Health to court.

respond to the HIV/AIDS crisis contributed to worsening gender and socio-economic inequities. This is because home care givers are predominantly women and treatment is most unaffordable for poor people as there are often additional or hidden costs like transport.

At the moment there is a clear tension between the immediate need to deliver services, which requires centralisation due to lack of skills, and the longer term development objective of strong local government, which requires decentralisation and more power to local stake holders. The decentralisation has however mainly occurred from the national to the provincial level, while the local level has been under utilised (Veenstra, 2007, p. 121). Local levels could have facilitated treatment with a better developmental approach to HIV/AIDS, due to their better access to communities and partners as well as their potential to include other community structures like TAC or CBR in their approach. This is particularly important as the number of Home Community Based Programmes (HCBP) has increased over the last 17 years (see feature 6.6) and these could have profited from more empowerment and self government.



Feature 6-6 Increase in HCBC programmes in between 1990 and 2005 (Naidoo, 2005)

One of the initiatives to help overcome the skills shortage in poverty stricken or rural areas was the recently introduced “rural allowance” and “scarce skill allowance”, which attempt to attract particular medical staff to these areas (Veenstra, 2007, p. 110). While this has shown success there would also have been a chance of making work placement for young staff on internship positions more attractive. As Veenstra explains in her thesis, these young people often get exploited and therefore leave the area as soon as they finish with their internship. The unfortunate experiences that some young doctors and nurses have had inevitably make their way back via the student grapevine and therefore some areas do not get any applicants for internships anymore (Veenstra, 2007, p. 113). Another missed opportunity is the wider training of hospital managers and principals. The limiting notion of a manager as a personnel administrator rather than a true HR manager has made people believe that motivation is not a management issue. Old hierarchical and rigid bureaucratic structures are still eminent and are generated by an authoritarian mindset, which in turn, particularly, drives dynamic and creative people away from these areas. The old structures need to be overcome as they are a hindrance to development and are also fragments of the master and slave ideology common in both Apartheid philosophy and the traditional Zulu kingdom.

6.2 THE CONCEPTUALISATION OF HIV/AIDS

And then the whole thing about this HIV/AIDS now. This misconception that if you have sex with a virgin then you will be cured of AIDS. … Now our children have reached a stage where they go for blood tests because we see all the signs but when they come back from the clinic they don’t show us their cards. That is the last time we see the clinic card and then we see the signs and inevitably it is followed by death. They won’t tell us that they are HIV positive. (Interview 11, teacher)

Apart from the mixed messages from the Health Minister Tshabalala-Msimang about vitamins, beetroot and African potato treatments there are still many myths about curing AIDS which need to be dispelled. AIDS and sex were taboo for a long time and as the extract above shows are still not openly discussed. Many misconceptions have therefore managed to find their way around. These misconceptions about causes and treatment of HIV and AIDS are various and differ from person to person. One aspect of these notions is connected to the Social Representation of women.

6.2.1 GENDERING OF HIV/AIDS

The variety of notions have their roots in the different explanation models that people choose, when explaining disease. In chapter 5, a model was developed about the Subjective Theories that people choose to interpret disability and disease. Just like any other disease, people will explain HIV and AIDS either in a natural or supernatural way. The concept of vulnerability offers the option of taking strengthening umuthi or pleading for protection from the ancestors to prevent misfortune, like HIV infection. The concept of pollution has, on the contrary, developed its own dynamics and influences Social Representations about HIV/AIDS. The concept of pollution is deeply connected to women's bodily fluid.

Conceptualising the notion of women's bodies at St. Wendolins, near Durban, Leclerc-Madlala (1999, p. 189) describes this notion as a "suitcase which conceals and transports disease to others". Women's bodies are believed to have more and better hiding places, especially through their wetness. A woman's vagina and womb is therefore often identified as a place where diseases like HIV/AIDS can hide and grow. Women in this context are seen as permanently polluted[10] or "dirty", carriers of disease and dangerous to men. By the same token pollution is still the dominant theme and an explanation for the cause of AIDS (Mills, 2005, p. 138), and as a result of this, women are often stigmatised for causing AIDS.

The notion about disease in the context of HIV/AIDS is often shaped through the understanding of biomedical germ/virus theories. Theories of different cultural backgrounds hybridise to a Subjective Theory of the individual. Theories can therefore shift from the supernatural cause to the natural cause. A biomedical explanation gets completed through the concept of pollution or vulnerability. The latter is seen as a transmitting factor.

"Germs" like HIV are seen as dirt that hides in bodily places and can be transported to other organs via blood and other bodily fluid. The polluted "stickiness" of the vagina is believed to hold these germs especially well and is therefore a place a man "would not touch". As women menstruate and menstruating blood passes through the

[10] This is not equivalent with the ritual pollution during pregnancy, after childbirth or death.

vagina, some dirt is believed to stick in the vagina and mix with the secretion (Leclerc - Madlala, 1999, p. 190). A man should therefore rather not have intercourse with a menstruating woman. This may also explain why one of my participants described that she was gang raped specifically because she was pregnant. The men in this instance could be sure that there had not been “dangerous” blood passing her private parts for a longer period. She was therefore considered as being “hotter than all the other women” as being “the best” (Interview 2) and with this as less polluted in the sense of being dirty.

Pollution also influences important events in men’s lives. In a discussion with a traditional healer I was told that the men will not sleep with their women before important events. Traditionally this would be before going to war. Again the re-occurring theme of pollution through women emerged out of my data. The pollution through women was regarded as dangerous and as having a weakening effect on a man’s body. Nowadays however this is transferred to important events like a job interview or a soccer match. Apparently this is the reason why soccer players do not take their girlfriends or wives with them on tour as is the custom of European soccer stars (Interview 20).

Eminent within the concept of pollution is the notion of “cleaning” or purification, which is used as a treatment or protection. There are a number of different “cleaning” rituals that range from deliberately caused vomiting (Ngubane, 1977, p. 112) to, as has been discussed in recent media events, ´virgin cleansing´. Rituals also shift with modernity. For example, after a funeral people would traditionally dip their hands into a special liquid consisting of bile juice from a slaughtered beast to cleanse themselves of umnyama (Ngubane, 1977, p. 123). The more modern version however is a plain bucket of water with soap, or the more luxurious version, a shower. The choice of cleaning or purification rituals however depends on the purpose of the cleansing and cultural interpretations of the particular situation. These decisions are often guided by traditional healers or spiritualists who can provide better answers for African people. As it stands today, African people can be quick in pointing out that science provides no sure answers for the origination of HIV/AIDS. AIDS educators still cannot answer the question as to why one person gets infected or sick at a particular time and the other one not. The concept of witchcraft and

pollution can provide a satisfying theory of the original causation. People therefore turn to their traditional healers for help. Some ´traditional´ medicine is believed to prevent HIV infection (Marcus, 2001, p. 116), probably through strengthening the body, while others are believed to heal AIDS. One of the herbalists that I interviewed explained his medicine to me in the following way.

I prepare a special mixture of garlic, African potato, and ginger, isibakla (a bark from the Hluhluwe area) and isihlungu samandiya and fill it in a bottle of 750 ml. They have to buy two bottles and use it within a month. Then they must get tested again and if his HIV is higher (probably meaning CD4 cells) then he is cured, if not he needs to carry on with the treatment. (Interview 20, traditional herbalist)

It should be noted that this herbalist seemed to have some biomedical understanding of HIV/AIDS, but that some basic concepts like HIV and CD4 cells were still being confused. Besides the ´bottle extract´ he also had a stone available, called ´itshe lamalonda´, that could heal boils and abscesses and this was also used for AIDS patients. Asked how one could get infected with HIV he named sexual contact as well as kissing and touching as transmitting situations. He also explained that witchcraft and pollution were factors that were responsible for spreading AIDS.

It must be mentioned that the treatment with African potato is quite a problem. Garlic, ginger and probably also African potato contain Antioxidants, a reactive group that scientists believe to be able to disrupt the virus DNA reapplication (TAC, 2005). On the contrary recent studies have shown that African potato (Hypoxis) and Cancer Bush (Sutherlandia fructescens) interfere with biomedical AIDS treatment and lower the levels of antiretroviral (ARVs). This means that the HIV continues to multiply and weaken the immune system. It also increases the chances of developing resistance to the antiretroviral (TAC, 2005, p. 2).

6.2.2 PAST AND PRESENT MYTHS

Myths seem to be created and disappear, leaving confused people behind, who are looking for a new explanation. Some of the myths that have slowly disappeared over the years include the belief that HIV was injected in Oranges, carried in condoms that are available for free in clinics, that white people brought the virus to kill black people

or that the new government purposely let the virus spread so as to reduce numbers (Tillotson & Maharaj, 2001, pp. 93-95). Even contraceptives like the Depo Provera[11] have been blamed for spreading HIV/AIDS (Mills, 2005, p. 140).

In 2006 a new myth appeared on the scene, when South Africa's deputy president, during a rape trial, claimed that he had taken a shower after having consensual sex with a woman he knew to be HIV positive (The Mercury 9.05.2006). A participant in my study explained to me that it would be within their culture to take a shower after sexual intercourse. The deputy president however explained that he "knew the kind of woman he was sleeping with and therefore took these preventative precautions". The shower seems to be the modern purification ritual after having sex with a ´dangerous, dirty woman´ that was obviously ´luring him´ into having sex. The theme of women being dangerous, out of control, loose or seductive is a re-occurring theme in South African society and victims of indecent assault, rape or unwanted approaches by men (at work, home or public places) will be victimised by these notions. Particularly in KwaZulu-Natal, men seem to have the imagination of themselves as being unable to control their sexual desires and that it is a woman's duty not to seduce them. In this context some high school pupils explained to me, that a "girl is asking for it", if she is dressed and behaves in a certain way. Men and boys, on the contrary, are believed to follow their natural and uncontrollable instinct. The then deputy president of the ANC had explained that it would be "unzulu" not to have sex when the opportunity arises (The Mercury, 5.04.2006).

The downside of Zumas trial is that it has left the impression in the masses that taking a shower after having sex may reduce the risk of HIV infection. Things could get even worse, if Zuma's current HIV status was revealed and was negative. This could be seen as a proof that the "shower" treatment works.

[11] This is a hormone injection that has a similar effect as a contraceptive pill.

6.3. A JOURNEY INTO SEXUAL CULTURE

You know first of all when you are a girl; you are expected to be a virgin, every time. So the first time, for the most girls, the first time is a disaster. … When you think about it, you don't agree. You know it is like rape. And in most cases you don't agree. You have a boyfriend and you say that you don't like any sex. But when he decides that it is time, that he wants to do sex, he can rape you, he can beat you. Before you even sleep with him. It is a forced thing. It is very rare that you agree on the very first time. Ja, but that creates a habit. You know when you are young, you get used to this, you penetrate this woman who is crying, who is angry, who is dry. Then you enjoy, when she doesn't enjoy. It becomes a habit, when we are young we become used to that thing. Then you grow with it, even when you are older, even if we agree now, Ok we love each other lets make love, no it is a habit. He will just penetrate you, without even touching without anything. You know and this creates problems. … They think, you know, sometimes they reject too, because you are wet. They reject you; they say what is wrong, because this one was wet. (Interview 1, woman with hemiplegia)

The heading of the Daily News on the 30th of June 2005, referring to new research, claims that HIV in South Africa is spread by sex rather than needles, razors or contaminated blood. This is a fact that was already well known in the world of HIV/AIDS research. Scientists can therefore scarcely ignore the sexual culture and practices as a contributing factor in the spread of HIV.

6.3.1 THE NOTION OF WOMANHOOD AND SEXUALITY

In chapter 4 basic gender relations were discussed. The patriarchal power relations between men and women have consequently shaped sexual relationships and culture. The history of political and criminal violence in the province has also had a major impact on people and seems to have brutalised gender relations. One of the first things that I had to realise was the fact, that for most Zulu-speaking women, sex was not fun. As a PhD student at the nursing department of the University of KZN put it: "most girls do not experience their first time as fun, in fact they do not even agree, the boyfriend just decides when he wants to have sex, she has no say" (break discussion). She went on to further explain that boys and girls learn that women do not have fun during sexual intercourse and perceive this as normal. Indeed all of my female participants reflected on this during the interviews in one way or another. The acceptance of domination as normal masculine behaviour was very obvious during the interviews. Even a married woman could expect to be abused by her husband. Sexual initiative is taken by men and the needs of women seem to be of no

importance. A participant explained to me that “the rules in her house were that when her husband needed her he would make a sign and touch her, and then she would know that she would have to be ready for sex” (Interview 5). When questioned about what would happen if she were too tired from working, she explained that her husband would become angry and “make it roughly”. It is interesting to note that the participant would have never dared to initiate “love”, as this is a male only domain. She was relatively happy with her marriage and would probably never have regarded the “rough sex” as rape.

Rape is very common in South Africa (Wood, 1998) and for some people a very difficult concept to grasp, because the dominating concept of male sexuality paired with the pain and disagreement of the female partner is deeply imbedded in the African way of life. So the question is: when is a rape a rape? Comparable to Europe 50 years ago, women are still judged by their appearance and behaviour and sexual obedience seems to be a duty of marriage. A woman that is wearing a miniskirt or walks around at night close to a tavern is regarded as loose and asking for rape[12]. No one will stand up for a woman like that.

The male on the other hand is just seen as following his natural instinct, not being able to control himself. This notion became very obvious in the already mentioned rape trial of the then deputy president Jacob Zuma in 2006. The accused claimed that the complainant “had seduced him and that he had to oblige because this was in line with Zulu culture” (The Mercury 5.04.2006). This explanation was accepted by the masses and even by the ANC’s woman’s league.

Another prominent example is South Africa’s worst serial rapist, Mongezi Jingxela, who was jailed in December 2007. Raping and assaulting 60 victims he showed no remorse and explained that he was “falsely accused”. In fact the sexual advances he made upon his victims were not his fault at all as “parents should have ensured that their children were at school and not roaming around the dumps.” (The Mercury 14.12.2007) Although this is an extreme case, it does however mirror the mindset that some men but also women have about women’s sexual rights in South Africa.

[12] It is interesting to note that this opinion is also widely spread amongst white South Africans, who regard their culture as being very different from black people.

Another popular case in KwaZulu-Natal was the assault of a woman in the T-section of Umlazi, Durban. The woman had dared to enter this section with trousers instead of a skirt. The angry mob stripped the poor woman, burned her hut down and assaulted her.

Having this background in mind it is very questionable if local campaigns against rape can be successful. A prominent example is the campaign during the awareness weeks for fighting “abuse against woman” every December. Men are advised on the radio and through advertisements “not to abuse women” without explaining what abuse really is. Although this campaign raises awareness it is very unlikely that men conceptualise this message, because the local culture regards certain types of abuse not as an abuse but rather as the right of man. By the end of 2007 this strategy had still not changed and T-Shirts were being produced, with the imprint “Satyagraha”, “Say no to abuse” ” and similar slogans, once again without explaining what abuse actually is. I am therefore not surprised that journalists like Omeshnie Naidoo observe that the campaign has increased awareness of abuse against women, but that the actual situation has not really improved (The Mercury 14.12.2007).

In the post–apartheid era streamlining and gang rape have become a very common phenomena. While one understands, under streamlining, the sexual disciplining of a women through a group of men, gang rape is usually conducted by a group of men that operate in a gang (Wood, 1998, p. 305). Streamlining can have different purposes. A man might want to teach his girlfriend a lesson, he might want to punish a girl for refusing his sexual advances or he might simply take advantage of a girl under the influence of alcohol. After he has had his turn on his victim he will then share her with his friends. Streamlining and gang-rape are brutal group bonding rituals that are made possible through deep sexist and discriminatory assumptions. The victim often does not report streamlining as rape, because she fears that people might ask what she has done to deserve it. In the case of streamlining she can also easily be blamed as she is the one that exposed herself to the abusive situation, by for instance following her boyfriend into his house (Wood, 2005).

In the era of HIV/AIDS male/female relationships seem to have been further brutalised. The notion of women being ´dirty´, ´dangerous´ and responsible for

spreading HIV´ has been discussed by Leclerc-Madlala (1999). Men fear the wetness of a vagina and prefer women with a tight, dry vaginal channel. Otherwise they might reject the woman, regard her as loose and not trustworthy. Some women therefore use a number of substances to provide the illusion of a clean woman. This is commonly known as “dry sex”. People get these substances from a herbalist or “inyanga” also known as a Zulu doctor. The necessary “umuthi” comes in the form of herbs, paste or powder (Interview 1). Leclerc-Madlala (1999, p. 197) also names Dettol and Savlon (a tropical antiseptic), snuff, bicarbonate and soda, toothpaste and plain salt as options for a “douche” that will make the vagina ´dry´ and ´clean´. Referring to this “dry sex” habit a participant concluded that this is one reason why so many women refuse to use condoms. As they are already dry the condom causes even more pain. Besides this, it is also very likely that it will break under such conditions, which maybe explains the common argument that condoms are not reliable. The result of dry sex seems to be very traumatic for the sexual anatomy of women and one participant put it quite clearly that a woman can be “limping for a whole week as a result” (Interview 1). Being in KwaZulu-Natal I had always wondered why some women have a trundling walk and sometimes I wondered if it had something to do with the condition of their genitals.

Violent sexual intercourse and the habit of dry sex could also explain why the women who were studied by Leclerc-Madlala (1999, p. 196) perceived the “whole female crotch area as a large festering sore, occasionally bleeding, often oozing and sometimes painful and itchy”. It indicates that there is a very high incidence of sexually transmitted diseases (STD), which in return encourages the persistence of the notion about the female sexual organs being dangerous, dirty and a carrier of diseases. Indeed a high prevalence rate of STDs is reported for KwaZulu-Natal. I want to emphasise, that this is not only a result of delayed treatment. Dry sex increases the probability of getting infected with STDs. The side affect of STDs and dry sex is an increased permeability of the skin for the HIV virus. It is therefore easier for the HIV virus to intrude into a person’s body.

6.3.2 THE “DIS-CULTURE” OF CONDOMS

Protected sex with condoms becomes under the above described circumstances even more crucial. Besides the painful experiences caused through rough and dry sex people refuse condoms for various reasons. Condoms are seen as building mistrust between partners and people believe that they can judge who has got HIV and who has not (Dladla, Hiner, Qwana, & Lurie, 2001, p. 82; Leclerc-Madlala, 1999, p. 195; Tillotson & Maharaj, 2001, p. 92). Condoms will therefore rather be used with an affair than with a more permanent partner, a phenomenon which is probably spread worldwide. Special to the Zulu culture is the tradition of multiple partnerships (Dladla et al., 2001; Preston-Whyte, 1996, p. 80), where a man can have several wives. In addition to this the migrant worker system and the ´lobola´ tradition have increased the habit of having several sexual relationships. Migrating to work keeps spouses away from each other for long periods. The African bridal money or ´lobola´ is for many unaffordable. On the one hand the average Zulu-speaking man in KwaZulu-Natal has to pay 11 cows or the cash equivalent (3000-4000 Rand per cow) for his ´lobola´. On the other hand a teacher earns approximately 7000 Rand a month and a labourer 80 Rand a day. Under these conditions it takes decades to save up for the ´lobola´ and this still does not take into consideration the necessary funds for a wedding and the various rituals that accompany the event. It is more than understandable that people still engage in sexual relationships and even have children long before they get married. Unfortunately living apart makes relationships fragile and provides the motivation for affairs (Harrison et al., 2001, p. 73). For men the idealistic notion of ´isoka´ (Casanova) gives an additional reason to have many girlfriends and is an especially dangerous ´game´ for a young man.

Another theme that emerged in my data is the notion that young women purposely try to get pregnant (Interview 6). The notion of proving womanhood with pregnancy and the access to a child support grant are often blamed as the cause for this phenomenon (The Mercury 20.07.2006; Interview 6, 17). How true this is cannot however be commented upon in this thesis. In any case young people seem to be engaging in unprotected sex and this is not always the result of abuse. This contributes to the spread of HIV in the younger generation.

Although Zulu-tradition embraces multiple partnerships, in the modern South Africa several sexual partners are not necessarily acceptable in a relationship. Men and women complain about the other sex not being trustworthy, but will not discuss this in their relationships. People engaged in a relationship will therefore find it rather difficult to insist on safer sex, as this would send the message that they do not trust their partner. Some people will rather take the risk of condomless sex. Otherwise they would risk an argument with their partner or the break up of their partnership (Tillotson & Maharaj, 2001).

Another reason for refusing condoms is the notion that condoms would cut down sensation (Tillotson & Maharaj, 2001, p. 93). Some people also fear that the fluid captured in them could be used by sorcerers (Preston-Whyte, 1996, p. 321). Leclerc-Madlala (1999, p. 195) describes the fear of some women that the condom could get stuck inside, move up in the body even as far as the heart or throat causing serious damage or death.

Because of this reluctance to use condoms, researchers like Preston-Whyte (1996, p. 318) and different African leaders wonder if the condom message will work in an African context. This is probably also a reason why the A of the ABC message (Abstinence, Be faithful and Condoms) is often promoted especially by political and religious leaders. My impression is that this does not seem to have the promised effect either. One way of explaining this is that abstinence similar to condoms is not perceived as an African concept either and is also not very practical and therefore encounters the same reluctance as the condom message. In addition to this, condom messages in the past have often been distributed in an, for African people, offensive and sometimes questionable way. In my opinion the problem lies rather with a lack of sexual revolution. Something that the African continent is only just beginning to see. A lack of stable relationships that have been built on equality and honesty is also noticeable.

Unfortunately some Africans could claim that equality, especially in a gender context, is not an African concept either. Here the concepts of respect and tradition seem to be of greater importance. In the fight against HIV/AIDS, gender equality and honesty between partners becomes crucial. European cultures have been lucky as they had

their sexual revolution decades ago and at the same time re-valued the position of women in their society. Automatically the sexual subject was lifted out of its taboo corner. The African cultures have not been so lucky. Here HIV/AIDS found its roots first, while people were still busy with reorganising the African continent. They therefore lacked the time to develop a culture that talks about sexual matters and would include the discussions of condom use or the handling of abstinence.

Even though people have started talking about HIV/AIDS, sexual matters are still highly taboo (Harrison et al., 2001, p. 70; Leclerc - Madlala, 1999, p. 43; Tillotson & Maharaj, 2001, p. 88). This contributes to the misinformation of the youth. One participant, who got pregnant as a teenager, explained that this happened because she had no guidance and information in this matter. She pressed the point that this "is still happening, because in the black community parents do not want to discuss relationship things with their children" (Interview 3). Most information young people seem to gather is from their peers, the media and sometimes from school. Concepts are not always fully explained and might be opposing. In the media, messages about safer sex and sexual messages in movies and adverts, might even contradict each other. Through peers, misconceptions can be spread and additionally confuse especially young people. In addition young people rebel to the strict traditions of their elders. Especially African youngsters want to enjoy their new freedom which also includes "playing the field". Older people find them therefore "difficult to control" (Interview 14) and feel helpless.

6.3.3 SOUGHT AFTER VIRGINS

Because of this confusion and the desperate need for solutions, people retreat to old values and proclaim for instance virginity as a solution to the spread of HIV/AIDS (King Goodwill Zwelithini about virginity testing The Mercury 12.09.2005). Virginity testing has seen a rapid rise in KwaZulu-Natal. In these tests the hymen is investigated. The young girl has to publicly spread her legs in front of her investigator, who announces the hymen to be intact or missing. It is made perfectly clear, for everyone, who is still a virgin and who not. Sometimes even A, B or C grades are given during the testing (Leclerc - Madlala, 2001, p. 540). Certificates are handed out or marks are left on the girl's skin. Lost virginity is punished with

exclusion and shame. Because of its intrusive practise and stigmatising results, a ban had to be laid over this practise in 2005. It is however still quite likely that the practise is unofficially carried out in some communities.

As a result of the proclaiming of virginity, virgins have become quite a sought after commodity. To protect their virginity girls will be especially protected and controlled. In KwaZulu-Natal they have even developed a fenced in village where the virgins of a particular Prophet can find refuge.

Men are especially targeting virgins, as they are seen as “pure”, “clean” and “fresh”. While HIV/AIDS is associated with “dirty” women (Leclerc - Madlala, 1999, p. 41), sexual intercourse with clean women, preferably a virgin, is seen as the appropriate “cleansing treatment” (Marcus, 2001, p. 116). Leclerc-Madlala explains this with the notion that a virgins vaginal track is ´dry´, ´clean´ and ´uncontaminated´, and a place where the “germs can not stick”. Besides this, the intact hymen is also believed to “seal” the vaginal track, preventing the HIV germ from getting into the girl’s womb (Leclerc - Madlala, 1999, p. 201). The notion about the good qualities of virginity makes men go out and especially ´hunt´ for virgins. It is suggested that this belief is a significant factor in the high rate of sexual abuse and HIV infection among young girls in the province.

Beside “being a cure” virgins are also regarded as “being safe”. Young women, who “play the field” know this and use this to their advantage. As one informant put it (Interview 3), young girls try to give their boyfriends the illusion of being “dry and clean” with other words the illusion of virginity. This is especially when they have more than one boyfriend and they use ´dry sex´ to prove their truthfulness.

The need for having more than one boyfriend is maybe caused by the need for additional income. This is especially when young girls are looking for entertainment. They may choose to have different boyfriends for different needs (clothing, food or cinema). The custom of playing with older men also known as ´sugar daddies´ (Dladla et al., 2001, p. 80; Harrison et al., 2001, p. 69) seems to be widespread. One participant mentioned, in this context, that “teenagers are actually not playing with each other that they are playing with old men” (Interview 6).

Some young men who, on the contrary, were infected from girls that “cheated”, can become very angry about these “loose”, “dirty” women and have in the past taken revenge and deliberately spread HIV to others.

In dealing with the youth there was …a group of boys from Kwa Dabeka who just had that belief that because they are HIV positive, they are not going to go down alone because it is the girls who gave it to them, so they in turn are going to spread it to other people. It was frightening. And just the whole HIV myth, this whole issue of wanting to take others down, is an issue of power, I am the man, I want you, and I must have you. You have no say. (Interview 11, teacher)

In 2008 hardly anyone in KZN can deny the affects of HIV/AIDS anymore or escape the influence of modern living. The hard facts that have been raised by HIV/AIDS and the influence of modernity seem also to have changed the way some people speak about and handle their relationships and with this have started to revolutionise sexuality. Through this relationships between women and men seem to be changing. There are couples in this province, who have gone their own way and with this have begun to revolutionise the local society.

Referring to this change, an HIV positive informant shared with me her life shattering story. Her previous boyfriend had raped her continuously and left her with a child. She was forced to drop out of school and encouraged by her mother to earn a living through prostitution. Somewhere along the line she got infected with HIV. However through the Treatment Action Campaign (TAC) and the influence of the local church she got information about HIV and managed to change her lifestyle. She later got involved with a man who was also HIV positive. Both of them seemed to have a very open relationship with each other. The respondent described how she discussed her sexual wishes and desires with her boyfriend and how they had discussed their HIV status with each other. As a result they protected themselves from re-infection via the use of condoms. The experience of HIV had changed the lives of both of them but they managed to change their attitude towards life positively and have become more open and honest in their relationship. This could easily be true for a number of South Africans that I have not managed to interview during my research. Especially in cities, African couples can be seen holding hands in the street and occasionally a couple is kissing. I make a point of this here as this is apparently not custom in Zulu

tradition. The concepts of truthfulness and respect are highly valued virtues for Zulu speaking people. They are being discussed within the background context of gender inequality and there have been some promising changes in power relations. Change is however still very slow and hesitant.

6.4 CONCLUSIONS

HIV/AIDS is still a mystified topic and people get different messages from different sources. On a macrocultural level the South African response to the epidemic can be discussed by looking at different paradigms and their relative appeal to people in power. A ´mobilisation/biomedical´ paradigm, as used by many scientists, emphasises social mobilisation, political leadership and ART[13]. The nationalist/ameliorative paradigm however looks at poverty, palliative care, traditional medicine and appropriate nutrition. The political discourse in South Africa seems to have given the ameliorative approach greater viability, which might be an attempt to support the "African Renaissance" and to find "African solutions". The extent of the epidemic however requires a more holistic approach. Social structures, leadership and the rollout of ARVs have to change in order to achieve this. The latter in particular is believed to have positive effects on the epidemic in general, as people will be more likely to participate in VTC[14]. It could also decrease risky sexual behaviour as it encourages spouses to discuss sexual matters more openly and decreases the anger of infected young men against women (Leclerc - Madlala, 2001).

Another empowering factor for people in general as well as people with disabilities could be the increase of skills used for subsistence and sustainable farming. This would also be a way of implementing the nationalist/ameliorative paradigm without compromising the ´mobilisation/biomedical´ paradigm. As many people live in rural areas or stay at home with little to do, a way of contributing to the family's income could be by tending the garden or nearby fields. Schools like the Harding special school in Harding (KZN) (Schwinge, 2001) or the Community Self Help project at the Marianhill mission station (near Durban) can be taken as examples and already

[13] ART – Antiretroviral Treatment
[14] VTC – Volunteer Testing and Counselling

inspire other schools and projects in the province. The empowering effect of learning such skills also has a promising side-effect in that it improves nutrition. One aspect that is highly important for people who are infected with HIV.

One opportunity that would bring people more power is the already emphasised method of decentralisation and power distribution to local levels. In the context of HIV/AIDS this is rather a difficult task, but it should nevertheless be given further support. One particular opportunity has opened through the HCBC programmes that may well integrate other initiatives and local structures such as CBR programmes and TAC initiatives. In this regard political will and a change towards greater democracy and participation would need to be followed.

On a microcultural level the tabooing of sexuality provides the perfect atmosphere for the spread of misconceptions, which are various in KwaZulu-Natal. Particularly the notion of being able to protect HIV infection through protective “umuthi” and the imagination of being able to “clean HIV” through sexual intercourse with a virgin have probably led to unnecessary infections. In addition to this the culturally related imbalance of gender relations and the dependency on male incomes have an immense impact on sexual relationships and have made women especially vulnerable to HIV.

On an individual level people need to renegotiate relationships. Notions about female and male sexuality need to be revolutionised. The Zulu conceptualisation of “respect” needs rethinking. If the perception of respect could be transformed into a concept that celebrates womanhood and manhood equally then sexual relationships would have a chance of being reformed.

7 DISABILITY IN THE CONTEXT OF HIV/AIDS

This chapter will look into the microcultural and individual level of the disability experience and its relation to sexuality and HIV/AIDS. In an attempt to place the thesis within the reality of local people this chapter will begin with reviewing the situation of teenagers in KwaZulu-Natal. In this regard the affects of disability on sexuality and the exposure to HIV/AIDS will be discussed. I will particularly outline the strategies that parents and caregivers have developed, while dealing with the sexuality of and the risk of HIV infection of their offspring. It is not difficult to see that issues concerning the development of relationships must inevitably engage in sexual themes, Social Representations about disability and living conditions for people with disabilities. Similarly, fertility, parenting and HIV/AIDS cannot be detached from themes that surround the topics of sexuality and relationships.

7.1 INTERVENING CONDITION – DISABILITY

7.1.1 TEENAGERS IN KWAZULU-NATAL

You can ask people. The HIV status in Marianridge alone amongst the teenagers it is just unbelievable. We always go back to where that person comes from. Most of us move out of the rut. There is no one to talk to the teenagers. In Marianridge they are sleeping around, they are making babies and you find this one is pregnant from this ones husband and these are thirteen and fourteen year olds. (Interview 24, abuse victim)

As outlined in chapter 6, it can be assumed that HIV/AIDS in KZN is mainly contracted through sexual contact (Gow & Desmond, 2002, p. 31). The example above shows that sexual activity also starts relatively early and is already widespread amongst teenagers. Being “out of the rut” is in this case associated with a sexual activity. This theme of teenagers having sexual relationships with much “older men” (Interview 6) or “husbands” (Interview 24) reoccurred in several interviews and seems to be of particular concern for parents and educators. In the academic literature, newspapers and reports, this phenomenon is usually summarised by the term “sugar daddies”, which is an older person who provides goods in return for sexual favours (Harrison et al., 2001, p. 69).

In regard to teenagers, another reoccurring theme in the data is the scheme of impressing other teenagers with being popular as a girlfriend and having lots of affairs.

It is like the behaviour like when I was in school I had so many sexual partners and I was doing it together with my friends and I in my group it was like who is our hero. Our hero is the one who has many boyfriends. So we were competing, who is having many boyfriends. It was very good. (Interview 14, HIV positive woman)

Interestingly the peer culture seems to differ quite tremendously from the way girls behave and try to appear in public, particularly when they are under the eye of the older generation or in the company of boys. The girls seem to pretend to have no knowledge about sex, as they otherwise would be seen as "lose" (Harrison et al., 2001, p. 75).

As already explained, teenagers in KwaZulu-Natal are enjoying their newly found democracy and interpret their ´freedom´ also as freedom of sexual expression. As the above mentioned participant put it "nobody can tell us what to do" (Interview 14). Intervening parents may even fear that their youngsters could report them to the police "try to punish us (the teenagers), we go to the police and say my parent is abusing me". TV and other media have undergone rapid change since the apartheid system was brought down. The apartheid prudery and invisibility of nudity and sexual relationships has been replaced within a few years with fast commercialisation of sexuality and relationships. These often offer little depth and teach little respect for one's own body or that of one's partner. One of the most prominent examples from latest advertisements is the "activating campaign" from Axe deodorant, where a whole plane was chartered in which some "lucky men" could enjoy being served by half naked goddesses. While the media presentation of sexuality through particular film material is relatively open as in other countries, public discussion about sexuality is almost non existent as the topic is still surrounded by taboos. This situation is confusing for the young as well as for the older generation.

Faced with two such contradicting extremes, teenagers seem to choose between either total abstinence or sexual revolt. While the older generation feels helpless as it does not have the skills to talk about sexuality nor does it have the power to control

its offspring. Comments about teenagers, such as they are “out of control” or that they “don’t listen” are therefore often heard.

As teenagers are among those people classified as sexually active it is therefore necessary to understand how they acquire sexual knowledge and what factors influence their sexual decision making. Traditionally Zulu people had an adult in their family allocated to take over the sexual enlightenment of their offspring (Schapera, 1946, p. 100). These sexual education sessions would be conducted with the entry into puberty. The educator would usually be of the same sex as the youngster. Some people celebrated puberty with special rituals. The readiness for having sexual intercourse was determined for girls with the beginning of menstruation. A goat would be slaughtered for this occasion. With this they would inform their ancestors that the girl was ready to get married. If she was still unmarried after the age of 20 another goat would be slaughtered to remind the ancestors to find her a husband (Interview 23). For boys this was done less specifically. In the Xhosa tradition, a young man would be instructed during the circumcision initiation. The Zulu tradition however does not know such a ritual. An older uncle would traditionally instruct the young man.

The close connection between families have however been slowly dissolved and therefore relatives are less available for taking over this important part of life (Harrison et al., 2001, p. 70; Leclerc - Madlala, 1999, p. 43). Many parents and here especially women raise their children on their own and do not have a man accessible for their children’s sexual education. Another problem emerges if the mother or father works long hours or far away from home. As a consequence they are not available for the sexual education of their children. Youngsters are often left with their grandparents or older siblings, who usually are not in the position to pass informed knowledge on either. To make it even worse KwaZulu-Natal is severely affected by HIV/AIDS with many fatalities (see Statistics South Africa 2006). Therefore there are only a few people left to look after the younger generation and child headed households are a problem in the province. These circumstances add to the severe misinformation of the youth. Most young people today grow up in a confusing world. As explained sexuality is still a big taboo topic in most families, while on the contrary it is openly displayed in the media and sexual abuse is a common phenomenon in

South Africa. On the one hand dress codes in institutions like schools are still very conservative, while on the other hand some people choose to wear provocative clothing in their spare time. Adults preach abstinence while on the contrary adults also assault and sexually abuse youngsters. In some areas a child cannot even feel safe at school as teachers and older schoolchildren have been involved in abuse. As a result many youngsters are confronted with double morals and misinterpret their environment, or struggle to develop appropriate behaviour with the other sex.

In such a world misconceptions and myths emerge easily. It is therefore not surprising that some youngsters think that girls with short skirts are asking for sex (see chapter 6), that one kiss is an invitation for sexual intercourse, or that you can only keep your boyfriend through sleeping with him (Harrison et al., 2001, p. 72). In conclusion it should be no surprise that misconceptions do also emerge about the sexuality of people with disabilities. This shall be discussed in the following sub-chapter.

7.1.2 COMMON MISCONCEPTIONS

But I know that the other woman was ill treated (in the hospital)*, the one that was also disabled. Their attitude there was very, very bad. Maybe it depends whether they know you or not. So the attitude was very, very bad. There is a myth, that disabled woman like sex too much. Even the nurses will say, ´heh´ this disabled people like sex too much. (Interview 1, woman with hemiplegia)*

Disability is a condition that intervenes within peoples everyday lives, consequently with their sexuality as well. Imaginations about the sexuality of disabled people are various. There seem to be two contradicting myths that are either based on the imagination that people with disability “are not sexually active” or “like sex too much”. The first myth is probably a result of the notion that people with disability have insufficient feelings, are intellectually incapable of sexual thoughts or simply just not attractive enough to be taken seriously as a sexual partner. The second myth is most likely based on the open approach towards sexual life that some people with intellectual disabilities practise. One of the participants explained it in the following way: “they don’t hide” (Interview 1), which in turn does not comply with Zulu culture where sexual topics are taboo.

Other myths expose people with disability to sexual exploitation. On the one hand there is the fear of people with "albino condition", the anxiety that disability can be passed on to the next generation and the stigmatisation that comes with being cursed by god or the ancestors (see chapter 5). These Social Representations about abnormality reduce a persons chances to engage in a stable relationships as they will not be chosen as a permanent partner. On the other hand there is the imagination that people with disabilities are free of pollution as they do not have sex. These make them vulnerable to "virgin cleansing" practices. A participant told me that "most people know that these are the fresh ones" and believe they are virgins. In an attempt to "cleanse" themselves of HIV/AIDS they rape these people (Interview 1, 15). The unfortunate result of all these myths is that people with disability get exploited, particular in a sexual sense. Being placed at the edge of society they are seen as easy targets and will be less protected.

It also seems to be widely known that it is very unlikely that one can be convicted of raping a disabled person. A participant explained to me how frustrated people that worked in the child protection unit in Ladysmith were. They got tired of interrogating rapists, especially the ones that raped children with disability, because they would get away with it anyway (Interview 1). Even if charges have been laid it is still very difficult to convict the accused, because people with disability often cannot stand as a proper witness. In the case of a blind person, identification is problematic. For deaf people there is often a lack of sign interpreters. People with intellectual disabilities, and here especially children, can hardly convince the court of the matter, so the rapist ends up getting off free of charge. What further complicates matters is the fact that the rapist is often close to the victim and can come from the same family. He could even be the family's main provider. A conviction would mean a loss of income and prestige in the community. The smaller burden seems simply to ignore the violation. One particular participant explained a case in which a caregiver had noticed that something was wrong with a child while changing a nappy. The caregiver talked to the parents of the then 8 year old child[15]. It seemed as if the mother already knew about the abuse, but chose to ignore it. As a result the parents took the child out of the day care centre and no charges have ever been laid (Interview 3).

[15] The child had a severe learning disability and was unable to control when she went to the toilet, hence the need for the nappy.

In another case it was known that the child's rapist was the uncle. Due to the fact that he was the main provider for the family the mother was put under pressure to drop the charges, which she later did. The people working at the day care centre tried to convict the uncle without the parents support (Interview 5). This however turned out to be very difficult as the intellectually disabled child could not stand trial. Hard evidence (biomedical) was the only way to convict the accused. It was only because the Day care centre was based within a clinic that it was possible to "collect" this hard evidence.

For women with disability this is not much better. Often left behind, being on their own and having less potential to defend themselves, they are targeted. A community worker and occupational therapist in a rural area explained it to me in the following way:

Smaller, weaker and younger people get abused. Most of the disabled woman, I visit, are pregnant and they say that they don't know how this happened. Like the one woman I visited yesterday. Her lower limps were paralysed, she couldn't walk, but she was pregnant and she didn't know how this happened. (Interview 13, occupational therapist).

His last remark that the woman did not know how it happened also indicates reluctance to talk about sexual things as well as the lack of sexual knowledge. Sexual education is for most African people, still a problem. A number of participants explained that in their culture they do not talk about sexual things and therefore gather no knowledge from their parents or other older people. All of my participants gave me the same feedback that there would be no sexual education in the schools in their area. They often differentiated between previously Model C schools (previously white only schools) and the schools that most African people visit. As Life Orientation is a compulsory subject these things should however be discussed not only in the previously Model C schools. It is quite likely that some teachers, because of their own difficulties with the subject, discuss the matter in a very sterile manner. In addition to this, schools seldom communicate about sexual education with the parents. There are some sexual educationalists that visit schools in townships and rural areas to educate about sexuality and HIV/AIDS (Interview 15). This however does not seem to have been made transparent enough and it is not a constant influence either, therefore not something that would stay in teenagers' minds.

7.1.3 ´LOVE´ AND PROTECTION

We had a case last year. There was a deaf lady who was sexually abused by a certain guy. When the lady went to the police station as a sign language person the police did not understand what her problem was. At the end of the day she signs and shows (participant points between the legs), and a police officer said maybe this lady is nervous. They lacked understanding. Then the policeman also took that lady and raped her again. (Interview 17, man with cerebral palsy)

For people with disabilities it is twice as difficult to gather information about sexuality and HIV/AIDS. In addition to this it is also difficult for them to express their own sexuality. Access to mainstream education and social life is still difficult and some people are even accommodated in separate institutions. Special aid and assistants is not always available even in institutions such as a police station. On the one hand the lack of necessary assistants can lead to misunderstanding and as the above case shows even to abuse at a police station. On the other hand as one participant explained to me, special institutions are often forgotten in mainstream programmes like HIV/AIDS awareness. They then have to make themselves heard so as to be included (Interview 5). There is also a lack of appropriate material, that can provide for the special needs of people with disabilities (Dube, 2004, p. 1). There is either no sign interpreter available or the material is too visual for blind people[16] or too complex for people with learning disabilities. The result is a basic access problem to sexual and HIV/AIDS education and knowledge. Some people with disability therefore battle to manage their own sexuality. This is especially true of people with learning difficulties who do not know how to express this part of themselves appropriately or lack the information about the right aid, protection and available assistance. For people with physical disabilities the question of condom use can be a problem, as their condition can make it impossible to use a female or male condom on their own (Interview 1). Using condoms, and with that being protected from HIV infection, is under these conditions very difficult.

Being at the edge of society, youngsters are easy victims of sexual exploitation, especially those with intellectual disabilities. Besides being very open about their sexuality, sexual expression also gives them an opportunity to draw attention to themselves. As sexual activity is encouraged within the peer culture (see above

[16] At the beginning of 2008 the African Union for the Blind published two training guides (AFUB, 2008a, 2008b).

chapter), they can easily fall within the trap of sexual exploitation. A participant discussed with me a case of a young girl that slept with several men so as to just be "loved" by someone. She explained that because the disability was quite obvious no one would care about her. When she "attached love" to her efforts of finding people to be with, she would however be successful. That was her only chance (Interview 1). "Love" and "sex" are often used synonymously by Zulu-speaking people. As the term sex is rather taboo the word love is chosen instead. "Being in love" or "romance" on the contrary are understood as true affection for each other. For youngsters however this terminology seems to be confusing and particular for people with learning difficulties it is difficult to distinguish between the two.

The problem of finding a life partner was mentioned by several interview participants. Having a disability seems to make people unattractive. Even more important is the fact that they are also seen as not being able to be a family provider. Due to the fact that marriage is often based on financial reasons, people with disability get a double disadvantage. This seems to be more serious for women than for men. A participant explained to me that a physically disabled woman would not be considered as a spouse as she was not believed to be able to look after her family and here especially the man (Interview 1). This in return increases the probability that people with disabilities engage in either no relationships at all or multiple partnerships. Taking into account that through their particular disability protection with condoms is difficult, the risk of getting infected with HIV increases.

Only in certain circumstances could this be different. As one participant told me, if an intellectually disabled woman is not "too ugly", she could get married, as she is believed to be able to do the housework. She would get married as a second wife and "lobola" would not have to be paid (Interview 15).

Confronted with an abundance of problems in KwaZulu-Natal, people with disability are far away from public focus. On the contrary and as the above showed they are very vulnerable to sexual exploitation, are treated by some people as sexual objects and in the case of learning difficulties often lack the ability to judge which behaviour is appropriate and safe. Parents, educators and people with disabilities have to face

the consequences of reality but have very different ways of dealing with this situation. Some of these coping strategies will be discussed in the following sub-chapter.

7.2 CONSEQUENCES AND PROTECTIVE STRATEGIES

7.2.1 WITHOUT A TRACE – DENIAL OF SEXUAL ACTIVITY

Prevent, don't allow alluring and condoms. I think giving condoms is teaching a child to use condoms. You teach him to be an isokha. If you teach someone to use a condom, what I believe in my opinion. I think if you teach someone to go far from sexual activity it is better than teaching him to use a condom because if you teach him to use a condom you teaching him to go and find more. (Interview 17, man with cerebral palsy, who was also a CBR consultant in a rural area)

As pointed out in the previous sub-chapter, the sexuality of people with disabilities is surrounded by two extreme assumptions in that people with disabilities are either "sexually not active" or "like sex too much". In the context of HIV/AIDS both assumptions deepen the denial of sexual development via denial of sexually related knowledge and opportunities.

The general population often finds it easier to simply deny the very existence of sexuality when it comes to people with disabilities. As the example at the beginning of this chapter shows, even people with disabilities themselves value abstinence highly and attach to "alluring" and "condoms" a negative stigma and interpret sexual activity as something that should be forbidden. The background to this interpretation is the notion that by teaching people about condoms you encourage sexual activity.

In the sense of the saying "let sleeping dogs lie" one chooses not to talk and educate youngsters with disabilities about sexual matters and rather preaches absolute abstinence as long as one has no permanent partner. Sexuality is moved into the private sphere and rather not publicly spoken about. This however implies that people with disability have free choice of when and where they have sexual contact, are able to acquire knowledge about sexuality and get opportunities to meet prospective partners in much the same way as able bodied people. While social life in general depends on controlling and constraining the body, through dressing styles and appropriate movement patterns (Turner, 2001), the management of sexuality is

highly socially regulated as well, but not spoken about. This individualism bedevils this topic and makes it impossible for people with disabilities to acquire appropriate knowledge and decreases their space for experimenting as their privacy is often compromised. As Seymour (1998, p. 128) observes, in her study of sexuality and disability, the individual is expected to take responsibility for issues that are often beyond her or his control. Despite the individualisation of sexual issues, private troubles become social issues as the following case study shows.

A CBR worker, who operated in the rural area of the Sisonke district (Interview 9), described and later introduced me to a mother and her physically disabled daughter. The mother of the disabled woman, saw her daughter as not being capable of "looking after a man" She felt devastated by the prospect of not having any grandchildren. As a solution she sent a brother[17] to penetrate her daughter. As a result of the abuse the young lady became pregnant and delivered a baby. The baby was however claimed by the mother of the disabled woman as her own. As the two women entered into a dispute over the rights to the child the CBR worker became involved.

It is also often assumed that youngsters with disabilities have no sexual desires. They are seen as incapable, or as life long children (Interview 10). In the case of severe learning difficulties people quickly judge that it is impossible to teach these people anything. People with these types of attitudes seldom talk or educate others about sexual matters. Even they are aware of the fact that especially girls are often victims of abuse, as the resulting pregnancy can not be missed. A secret approach to dealing with "the problem" is sterilisation. Even though this is no longer official policy, institutions and parents still seem to choose sterilisation as an easy way out (Interview 11). Caregivers and parents feel hopeless and have no trust in the judicial system, so sterilisation gives them at least the illusion that nothing is happening.

In both of the above examples the disabled body is handled like an object. The body itself is however central to sexuality. We need a body in order to be sexual and therefore intimacy depends to a large extent on the body. For people with disabilities the most intimate aspect of embodiment, sexuality, is subject to significant control by

[17] The African concept of brother is broader than the European one. It is therefore not clear if this was a brother of direct lineage or just a half brother.

others. Even though there are cases where disabled men are abused by women (Interview 9), women with disability are more vulnerable to abuse and less likely to be chosen as a permanent partner (see chapter 4 and 5). Most of the men with disability, which were interviewed by me, had some sort of permanent partner while none of the women with disability did. As Seymour points out in her study of people with physical disabilities, a woman with spinal injuries experiences much less practical sexual dysfunction than a man yet her reproductive opportunities may be much lower (Seymour, 1998, p. 129).

This is because society influences the ideas, values, bodily manifestations and social practices associated with sexuality. In the Zulu society the traditional role of a woman is to bare children and to be able to look after the family while physically working hard both in the field and in the house (Interview 3). This can partially be fulfilled in spite of a disability. While in a ´western´ context the "physical advantage[18]" of women with disabilities shows itself to be an empty blessing in terms of her reproductive opportunities (Seymour, 1998, p. 130), women with disability in KZN seem to have the same chances of pregnancy as their able bodied sisters. This however is not necessarily a result of more acceptance but rather the effects of abuse, exploitation and the option to be chosen as a second wife or as a lover (Interview 15).

In reality the behaviour of youngsters with disabilities does not differ much from the general behaviour of teenagers. When asked to describe her relationship with boys a girl with a learning disability answered that they (meaning the boys) are "wild" and that they "play around with girls". The same teenager explained that the girls are "fighting" about the boys, which can become very physical. Teachers and caregivers at the school, which was a special school, felt helpless towards their pupils sexual activities and therefore separated the girls and boys into different classes and attributed certain areas of the school for boys and girls only e.g. certain staircases. The conflict and curiosity between the boys and girls was however just moved outside of the school. The school then decided to let boys and girls leave the premises at different times. The conflicts and experimentations were therefore moved even further away from the influence of the school. The teenager herself reflected that she did not get any sexual education from the school. For the school, making

[18] The physical advantage is her ability to have sexual intercourse and to bare children, while this is considerably more difficult for men with physical disabilities.

sexuality invisible at the premises seemed to be easier than dealing with the problem.

The failure to educate about sexually appropriate behaviour can have very serious consequences as the next case study shows. The interview partner a CBR consultant (Interview 1) explained the situation of a neighbouring girl (P.), who had a severe learning disability. The mother and the school had failed to educate P. about sexual behaviour. Abstinence was offered as the only option and the mother denied her grown-up daughter the chance of having a boyfriend, although this was recommended by a friend. Never the less P. did manage to find her ways and was frequently found with men from the local tavern. They took advantage of the desperate girl and had sexual intercourse with her on different occasions. The experience of being wanted and "loved" for once in her life, while nobody else had bothered, made sexual contact very precious to her. The result was however that P. got infected with HIV, and at the stage of the interview, her health was quickly degrading. People did not openly talk about it and the fact that she was HIV+ has never been disclosed. For a trained eye the signs were however very obvious[19]. For the outside world she was a disabled girl that had become very sick. People wondered about her condition but nobody approached the actual problem. She was never sent for testing or counselling. The denial of her positive status has probably also resulted in her developing AIDS and not being treated with ARVs[20]. The girl died in 2006, officially of TB.

Other interview partners reported similar cases. What always stood out was the desperate attempt to protect the children or youngsters from sexual abuse or exploitation. The denial of knowledge and independence has however made the situation even worse. The high reluctance to get tested for HIV adds an additional problem, as without knowledge about the infection, treatment will not be taken.

[19] Most people with full blown AIDS suffer from similar diseases such as: chronic diarrhoea, oral candidiasis, pulmonary Tuberculoses, Pneumonia, unintentional weight loss (>10%), Herpes simplex infections, Kaposi´s sarcoma (KS) … see also Appendix 10.

[20] ARV or antiretroviral therapy is the only medication available at the moment for the treatment of AIDS. ARVs are given to people who's CD4 cells are less then 200 cells/mm^3 or who have developed AIDS in Stage IV (see also appendix 10a and b). The medication keeps the virus under control so that the person recovers and can once again produce more CD4 cells. The medication is subscribed over a life time.

As described, caregivers and teachers feel relatively helpless and are unable to deal with the sexual expression and activities of their youngsters. In general the older generations try to encourage their offspring to:

- delay sexual activities and stay virgins,
- be faithful to only one partner (particularly girls not so much to boys).

In addition to this the older generation might:

- reinforce certain gender stereotypes (particularly work related),
- try to protect particular girls from pregnancy and abuse,
- revalue and retreat into ´African´ traditions.

Besides all their normal efforts, teachers sometimes have to also deal with rape and other issues that unfold in toilets and school buses. It is interesting to note that the same teenager, as mentioned earlier, observed that the boys would be “naughty” anywhere, while the girls would behave as long as they were watched in class, but became ruthless as soon as they were unsupervised (Interview 21). So it seems the girls, who all had some sort of learning disability, knew very well what kind of behaviour was expected by the adult population and were also able to differentiate between school and spare time. The peer culture however seemed to set completely contradictive norms which are:

- materialistically orientated
- abundance of sexual encounters as admirable[21]
- relationships to the other sex as being predominately sexual

As a result of these contradicting norms young people with disabilities develop double values in much the same way as their able bodied peers. On the one hand the boys “naughty” behaviour seemed to have been accepted by the young girl as normal masculine behaviour. The phenomenon to accept sexual violence as normal masculine behaviour (see also chapter 6) has been discussed by many previous

[21] Girls seem to differ quite widely in their views about sexual activity. While some girls admire girls with plenty of boyfriends others value virginity and abstinence. The tabooing of sexuality might have made sexual topics particularly interesting for teenagers.

researchers (Harrison et al., 2001, p. 69; Leclerc-Madlala, 1999, p. 41). Caregivers and parents on the other hand feel helpless and try to remove their offspring's sexuality as far away from themselves as they can. As previously described, sexuality in the new South Africa is still taboo. Sexual education only happens during so called AIDS awareness workshops. The ABC message is brought across and nearly every teenager, except for some with disabilities, can preach it like a poem. Teenagers often do not know how to engage with the other sex and therefore seldom know how to negotiate friendships and sexual relationships. In fact they often do not know the difference between the two. Abuse, particularly of children, women and people with disability as the weakest link in this chain, is therefore persistent (Interview 24).

Overprotection was another re-occurring theme that presented itself when evaluating the data. Even though sexuality is a taboo topic the widespread danger of rape and abuse is known to most parents. Parents therefore might try to deny their youngsters any type of relationship with the other sex. Assuming that their children are asexual every sexual encounter or development of a relationship is interpreted as abuse, as the following interview extract shows:

And then the abuse comes where it is like you do not have a chance to do what you like and maybe your parents can think it is abuse but it is not abuse. Sometimes it is not abuse… Maybe I am 21 or over 21. Maybe like the parents won't let you have your own boyfriend or your girlfriend you know then maybe you take your own decision. You do whatever, the parents will think it is abuse. They think for you because they are the parent. (Interview 10, teacher)

The words "don't have a chance to do what you like" and "they think for you" shows to what extent youngsters with disabilities are influenced by their parents with regard to their sexual expression. Youngsters however have a strong wish for independence particularly when it comes to their intimate space and "take your own decision" and "do whatever"[22]. This is not always approved of by the parents, who then might report the incidence to the police or other officials like school principals. They in return have to figure out which abuse was a real abuse and which one not. This can however be a very difficult procedure particularly if the person involved is a person with severe learning difficulties.

[22] Notice sexual themes are not mentioned directly, the person talks around it. This is a typical way of expressing sexual themes in Zulu-culture.

As an example, chapter 6 showed that even police stations are not a safe haven for a rape victim. Even though the described rape was an extreme example, there are many known cases where the police have either worked together with the rapist or refused to record the offence (Interviews: 1, 5, 22). Interview partners reported that the police were either tired of recording abuse of disabled people as it would not have any consequences anyway, chased people away, knew the suspect and wanted to protect him or they were simply too lazy and careless to be bothered as the next example shows.

What happens is that in many cases in the past, cases were reported where the woman was there. They did not have a lady that could examine her and in some cases a report was not even made. Some of these people were chased away. The same young man that I spoke about (person with physical and learning disability) he was assaulted one day and they phoned me from the police station to come down because he was there. When this police officer was talking to me it was as if he was giving them trouble. When I got there I discovered that he was assaulted (meaning sexually abused) and he was full of blood and they wanted to get rid of him. At that time they never even wrote anything down that he was reporting. When I got there I forced them to make a report and go and arrest the person that assaulted him. He was full of blood but he was actually chased away. Somebody in the station phoned me because he mentioned my name. So I went down and rectified that problem with him. (Interview 22, priest)

In this case at least a report had been made. All too often the caregivers or relatives fear serious consequences resulting from a report. Especially in the case of children and people with disability it seems that a charge is not made or withdrawn because the offender is too influential or the family depends financially on him. Often victims and caregivers are also threatened by the offender or fear they could be targeted if they report the abuse. The following two cases that occurred during the time of my research are recorded here for illustration. One of the teachers that I befriended during the course of my research had to change both her home and the school at which she taught when entering a witness protection program. She was high jacked several times in an attempt to silence her after having witnessed the abuse of a pupil whilst at school. Another very sad example is the story of our housemaid's niece who was "messed with" by her brother, after she lost both parents to AIDS. The abuse was never reported and the girl may even have to go back to her brother. The fear of being targeted for reporting the crime was tremendous as the young man was known to be involved in crime. In an attempt to protect our own families the crime was never

reported. As in this case, looking away and ignoring the problem seems to be the path of less damage, so people choose not to trace down the offender.

In the case of people with disability incidences of abuse are reported even less frequently as people assume that people with disabilities either "don't mind", "were looking for it" or should "count themselves lucky". Intimidation and stigmatisation is also connected to abuse and of concern particularly for women with disabilities, as the next example shows:

Especially when you look at a woman that was perhaps raped she doesn't want the whole world to know that she was raped. She still has a life ahead of her. It goes then that these people don't want to come out and that is why many of these cases were not even reported. Simply because in one way their lives were threatened. The other way they don't want people to know their story and the third thing is that they get little support from the police and all such things. They say especially if you are a woman that you were looking for this kind of thing. (Interview 22, priest about abuse of people with disabilities)

No contact between the sexes, sterilisation and/or no charges against the offenders, seem to be a way of dealing with the issue of sexuality. The case of abuse therefore cannot be traced. The cruel reality for people with disability is a higher risk of abuse and HIV infection and a lesser chance for AIDS related treatment. This ultimately results in a lower life expectancy and a loss of dignity.

7.2.2 THE AWAKENING TALK – SEXUAL ENLIGHTENMENT

I taught him, he used to masturbate in the bed. Then I told him, if you have this feeling in your body, it is not wrong to masturbate. Ok, but just go to the toilet, just close the door and do it there. Clean yourself up and come and sleep. Because now I can see that he has feelings. But I teach him about sex also, about how to use a condom, about why you have to use a condom. It is not necessary for him to start and sleep with somebody now. He has to sleep with somebody when he is 24, 23 years old. You know he understands all that. But he can have a girlfriend that understands him like that. Even at school they teach him like that. (Interview 2, mother of boy with severe learning disabilities)

Discovering their sexuality is a challenge for every teenager, including those with disabilities. Youngsters get different types of support from their parents and caregivers who either pass or do not pass on knowledge. This depends on their values, knowledge and personal openness towards the subject. There are of course various degrees of openness towards sexual education and one cannot divide

caregivers and parents simply into people that educate and that do not educate about sexuality. To illustrate the difference of educating or not educating I have chosen for this chapter parents and caregivers that have developed a very progressive approach towards their youngsters and take particular care to inform them as well as people with disabilities that have taken a responsible attitude towards their own body and sexuality.

A change seems to have been brought forward especially through the awareness of the AIDS and abuse problem. These parents have realised that their sons and daughters are having a sexual life no matter how desperately they would try to avoid it. They have also realised that they as caregivers have a high influence on the way their offspring develop. Often they are in the dilemma of having to raise their child as single parents. Nevertheless they have decided to take matters into their own hands and try to give their children some basic sexual education. They try to openly discuss sexuality and sexual practices. Faced with the brutality of everyday life in KwaZulu-Natal many parents however still bring across old stereotypes. Boys get taught how to use condoms (Interview 2) and girls get taught how to say no and to speak up about incidences when they are "not comfortable with a person" (Interview 3). The protecting element is even here the dominant force and not the sexual enlightenment. This however I would account as a natural desire for every caring parent.

Interestingly enough there are also some adults with disability, who reflected on their sexual situation and found their own empowering approach. These adults however also came from privileged backgrounds, had liberal upbringings, went to mainstream[23] schools and enjoyed co-education (Interview 1, 4, 6, 7, 9). What they had in common was a positive attitude towards their bodies. They very openly compared themselves to able-bodied people and the type of relationships these people had. Often during a narrative interview section, they would explain how they had started off their lives with depressions and complexes about not being worthy of a relationship. After realising that the able-bodied people also had problems in their relationships and through acquiring more information about sexual matters they developed a more positive approach towards the possibility of a relationship.

[23] Mainstream schools are public schools that are built to accommodate all types of learners as opposed to having children with disabilities in special schools.

At the time of the interviews these male participants were in a permanent relationship or marriage while the one woman in this group had a child and had chosen to be a single parent. This however also reflects that with a positive attitude towards life and some financial stability it seems to be possible for a man to find a life partner, while it seems to be almost impossible for women. Asked about this phenomenon a participant (Interview 1) explained that there are two reasons for this. Similar to European culture (Seymour, 1998) African-men "are not confident with the disabled body" (Interview 1). Women with disabilities are often seen as unattractive and do not fit the stereotypes of a ´normal´ female body. A woman who is experiencing severe bodily damage or dysfunctions must remake her embodied self within very rigid social categories. In addition to this African woman are expected to work hard and "look after their men". A woman with a disability might not be seen as being able to fulfil that role. She can therefore only hope to become someone's second wife. Faced with the harsh reality of the social construction of a sexual woman and wife it seems to be almost impossible for a woman with disabilities to present her self as a worthy partner. In addition to this remnants of conventional romance and courtship continue to impoverish women's sexuality. In waiting to be pursued by a man, women allow others to assume responsibility for their sexual desires.

Motherhood was also experienced as empowerment for some women. Giving birth to a child meant taking responsibility for a new life. As the following example shows this enabled some women to re-evaluate their own situation and help gain respect for themselves.

You come to a point when you think God all these men are using me, no one is making a commitment to me and that is not my life. I am not meant to live this life. You sort of grow up. Especially when I had my first child people were looking at me now. I don't want people to talk bad to my child about me and say your mother is a bitch so maybe I just grew up. (Interview 24, woman with physical disabilities)

As the above mentioned case shows, "growing up" was associated with responsible sexual behaviour and protection, which probably saved her life in the end as she has not as yet been infected with the HIV virus. It can almost certainly be assumed that if she had not stopped trying to acquire "love" through sleeping with men she would be HIV positive today.

For a man with a disability this is much easier as his traditional role only demands that he be the family provider and household head. This may be difficult enough in a country with a high rate of poverty, but as soon as a man with a disability earns a salary of some sort he will be seen as attractive. With the disability grant as one option to earn an income this is possible for many men with disabilities. The biggest challenge for men's self image might be the threat of not being able to obtain a penile erection, as this symbolises a threat to masculinity itself. The following extract was chosen to illustrate this.

Would you go with a disabled man? No. No one wants to be together with disabled people. We are not attractive and we don't get healthy children. Only if you have money it will change. But then this is not the true love. They only love you for the money. … How can you sleep? How do you sleep? Questions like that. … Do you stay in your wheelchair? Do you sleep here? (Laugh) How can I sleep here? (Laugh, points between his legs) Have you ever gone to the toilet? Some questions like that. Foolish questions. … They are not sure whether you are a man." (Interview 9, man with spinal injuries)

The association of masculinity with penile erection might be particularly strong in Zulu culture if one recalls the previous chapter. Sexuality, even though it is felt as an embodied passion, is also a product of learned features and Social Representations in a particular social context at a particular historical time. As can be seen in the previous example the participant himself questioned if he was attractive enough as a man. It shows that it is infinitely difficult to challenge social categories in relation to masculine and feminine sexuality, but he had to face and overcome this task. His immature behaviour during the interview (laughing) accounted for his own loss of self image (disability was caused through a mine accident) but also illustrates how highly taboo talking about sexual matters still is today. Words like sex, penetration, penis and so on were not used by any of my interview partners, who preferred to talk about "love", "sleeping", "have feelings" or "being messed with". This is not an account of a translating mistake but an account for avoiding talking about sexual things. In Zulu itself, words to describe the sexual anatomy and physiology do not exist. The participant however managed to overcome these barriers and has now married.

Common concepts about masculinity like aspiring to be an ´isokha´ is also entrenched in the way men with disability like to see themselves. As the following example shows, men with disabilities might practice risky behaviour and have various sexual encounters just like any other Zulu men.

In fact being a male sometimes ladies are usually a threat, a fall down. Especially these days if you go for this one it means that you usually take a spade and dig your grave. That is why now we are not involved in this. Especially for me it was my downfall being a lover boy. Now because I am one of the leaders in my congregation it hinders me. I mean I was just like a isokha. If you want to keep yourself happy you must run away from ladies because sometimes they cause headaches. If you do have more than two the first one will come with problems and the second one just the same, the third one also. (Interview 17, man with cerebral palsy)

Similar to the previous case of the woman after she gave birth to a child, this man's behaviour changed after he took over an important responsibility in his community. Reflecting on his behaviour he knew that his sexual explorations were life threatening or as he expressed he would "dig himself a grave" and it would be his "downfall". With the latter he means HIV infection or any other Sexually Transmitted Disease (STD). Again and as this example shows sexual themes are not expressed directly as this would mean breaking a taboo. Instead the participant prefers to use words like "threat", "fall down", an unspecific "this", "ladies", "problems" and "headaches".

A concern for many caregivers is the sexuality of people with learning disabilities. The way of dealing with their sexual development is somewhat devided. Besides ignoring the fact that they need education in this area some people choose a different route and provide the space for discussion. The openness towards the subject is for caregivers both a challenge and an opportunity at the same time. Usually caregivers described these young people as "straight" or "open" (Interview 1, 5, 22) as they are people that talk about sex without shyness. This is often interpreted as abnormal and not in line with Zulu-culture (Interview 5). As the following example shows some caregivers find it very important that disabled people come to them with all their questions (Interview 22) and not to the wrong people who could take advantage of them.

I know even mentally disabled somebody who one of the companies employed now, she comes quite often here and she will sit with me and ask me certain questions. I always encourage her rather to come and sit here and ask me or my wife the questions instead of going around and ask somebody else. She can one day ask the wrong person and she will have the wrong answer and maybe something will happen to her. She is 22 years already so she is a big girl. So it is all these kind of things that are taking place but other than that we really want to do more than what we are doing now. (Interview 22, priest)

The protection of people and here especially girls and women with disabilities seems to be the major motivation. Whatever the motivation was to provide a platform to talk

about sex and relationships it seemed to be an important catalyst for people with disability and an encouraging factor while developing safe and pleasurable behaviour.

To finish this subchapter I would like to quote one teacher who saw her responsibility to educate her pupils about sexual relationships and included this in her Geography and History lessons. As the previous examples showed, once people with disability are able to take responsibility for their own life, once they move out of their passive role and participate in society accordingly, their sexual behaviour will also become less risky.

You see I mean in the sense that even though they are school learners the key thing is for each of us to take responsibility for our own lives. We always ask the children" What do you want from life? When you come out of this special school these are the challenges that you are going to face because remember you are only going up to grade 10 here. Your friends are going up to grade 12. You can't go to university so you have to become the best you can within these limitations. This is the world out there. There is the threat of HIV/AIDS. There is the threat of a pregnancy. Are you going to be able to look after a baby? This boy is not going to marry you. He didn't promise you get a baby and I am going to marry you. So the solution is for the learners to take responsibility for their own lives. And unless or until they do that then I believe we are going to continue very much as we are. Because you can, I don't' believe that it is lack of knowledge that is causing the problem. It is just not behaving appropriately, not taking responsibility for your life. You decide your destiny; somebody else mustn't decide your destiny for you. And have realistic expectations, don't think if I have sex or I fall pregnant from this guy he will stick with me because he is not. And the boys as well at that young age are in one sexual encounter I could be signing a death sentence. And until that sinks into their heads, that is the only time change will come." (Interview 11, teacher at special school)

7.3 THE INVISIBLE

7.3.1 PEOPLE WITH DISABILITY AND HIV/AIDS

I know some of them they are not well educated to understand about sexual transmitted infections and so on. So they have been greatly affected. I know a number of them who passed away because of HIV where they will say no I have tuberculosis or it is just a cough but you realise that it is not just a cough. (Interview 4, man with spinal injury about people with disabilities)

As already explained in chapter 3, I encountered a number of barriers in approaching valuable interview partners, mainly because of safety issues. Usually it had not been a problem to find willing participants who were either HIV positive or who had a

disability. One of the obstacles in my research was to find people with disability who were either HIV positive or a victim of sexual abuse. In addition to this the person had to be prepared to talk about their situation. It was often easier to find a person that would explain the situation form a third party perspective. One reason for this phenomenon is surely the double stigmatisation that is attached to a person with disability who is also HIV positive. The following example illustrates how dangerous it can be to open your HIV status.

We currently now especially in this age we are really pushing to get people to the understanding of especially HIV/ AIDS because there are still a lot of ignorant people around still that sort who have certain beliefs, that these people (meaning HIV positive people) are not supposed to be around in the community. … Well there were incidents people actually came together and walked to the places where the people live and said: "listen here we want you out of the area" That I know. (Interview 22, priest)

To be forced out of their area provides a double threat for people with disabilities as they are not only losing their families and friends but also their entire support system, which they need even more than others. People with disabilities are therefore very reluctant to talk about their status and parents prefer not to face reality. In fact the people that did allow themselves to be interviewed did so only because I was a European face with a foreign accent. They were sure I would not talk about them as I did not live in their community and was not of African descent (Interview 25).

African interpretation of disease has often added to the negative interpretation of HIV/AIDS (Leclerc - Madlala, 1999, p. 44). As explained in chapter 5, disease as well as other misfortune can be explained by spiritual/supernatural influences. In the case of AIDS two interpretations are possible. On the one hand a person with AIDS can be seen as being bewitched by someone in the community. On the other hand, and as the following example illustrates, a person with HIV or AIDS can be seen as the cause of other problems in the community and this even further threatens their acceptance in the community.

I think it is more in the black culture where we got doctors they have sangomas and witchdoctors. These people pronounce it and blame it on certain people. Because they were saying it and people have trust in them so they sort of swiped the people and convinced them that the AIDS people have to be removed. (Interview 22, priest himself being "black")

People with disabilities suffer from such harsh exclusion especially considering that their disabilities have already placed them at the edge of society. To illustrate this effect I would like to quote from the following case study. In the interview of a man with a hearing disability it became apparent that as long as the man only had a hearing disability and his HIV status was not known, his wife stayed with him (Interview 18). After having found out about his positive HIV status his wife left him and their children. One of the children was also HIV positive. The man struggled with the degradation of his own health and the responsibility for his two children. He had to move in with his parents who took care of him and the children. Most of his friends left as they did not want to have anything to do with him anymore. At the time of the interview he was close to death and the interview had to be limited in time so as not to exhaust him too much. He had started to take ARVs which he was able to collect at the district hospital and which apparently had already improved his health. Even though this medication was free it was still an effort for him to collect it. He had to travel several kilometres to the district hospital, which costs him between R80 and R200 a month. This was costly as his only income was a disability grant of R780 a month. With this he had to clothe and feed both himself and his children. To acquire a hearing aid was therefore out of the question. He cared for the children to the best of his ability but had to rely to a large extent on his parents. This he experienced as very offensive because he could neither fulfil his role as a father nor the traditional role as a homestead head. He experienced a loss of respect even from his own children, which is particularly insulting in Zulu culture.

I feel respected but at the moment at home there is no respect because my children are possessed by my parents just because I am sick and I am deaf and I can't walk. Eventually the children don't respect me and they only respect their grandparents. They don't respect me because of my disability and my sickness. (Interview 18, man with AIDS and deafness)

It is interesting to note that the word respect reoccurs several times in his description and as I described earlier it is a very important concept in Zulu culture. Respect is often understood in the sense of listening to or obeying someone like parents or a husband. The children of the participant often did not listen to him as he was too weak to apply any consequences to their behaviour[24]. On the contrary the grandparents were able to do so and he therefore experienced his children as being "possessed by" his parents. The loss of respect through his disability and sickness

[24] Traditional disciplining of children is done with a stick or whip which is also called a shambok.

(AIDS) can also be interpreted as a double burden. Two burdens that together make life very difficult for him.

These burdens were also often described when it came to victims of abuse, who also had disabilities. As described earlier a large proportion of rape cases are not reported for several reasons and when some cases do make it to court, they are often silenced in the process. The court attendant that I interviewed reported several such cases to me. She reported that especially in "black communities you find abuse of these disabled children" (Interview 24). Often a close relative like a stepfather is abusing the children and all too often the mother withdraws the case or makes the child "disappear" for the duration of the court hearing. Due to the fact that she has to depend on her husband or boyfriend it is easier to withdraw the case than to risk losing the income of the family provider. Particularly for a mother of a disabled child that is already stigmatised through the child's disability this seems to be the better choice. Otherwise she could also risk double stigmatisation. With the withdrawing of the case the victim's voice cannot be heard and the case becomes invisible.

7.3.2 NEGOTIATING SEXUAL RELATIONSHIPS

They said my boyfriend doesn't want to take the condoms. But I said, this is the third child. And then we talked and after six months that one that had accompanied the one who was pregnant was also pregnant. And I asked, why are you now pregnant. And that one was very honest. She said you know what, ´Amacondom afunane …´, when you are a woman - man don't want a condom. So he is working, he got money so I do whatever he says I must do. That is why she doesn't use a condom, because he doesn't want to. (Interview 1, CBR advocate about two deaf women)

The problem of negotiating safer sex has been mentioned in several writings about HIV/AIDS. As it stands in the African culture, sexual decisions are made by the dominant person, which is most of the time a man or the person with the highest family income (Harrison et al., 2001; Leclerc - Madlala, 1999; Preston-Whyte, 1996). Gender imbalance and financial power can give a homestead head so much control over his family that he (most of the time a man) can dominate the rest of the family. In the "bedroom" this means that he can make the decision when and with whom he chooses to "play". His family depends therefore on his upbringing and values. In addition to this the African culture interprets condoms as a sign of mistrust and several other myths revolve around the subject condoms (see chapter 6). Insisting on

a condom, under such circumstances, is often seen as disrespectful. The mainstreaming of condom use is therefore very difficult and as the example above shows depends on the decision of the homestead head.

For people with disabilities this situation is even more desperate. In general it is much more difficult for a person with a disability to find a partner, which also reduces their chance to "be picky". They are therefore much more vulnerable to exploitation. As one participant described it to me, because of his disability grant, women used to come to him and "share" his grant with him. He also expressed that this was quite a common phenomenon and that because of this people with disability remained "bankrupt" as all their money would go towards women. He also explained that he was married now and chose not to play around anymore. Condoms were not used in his family as they were a sign of mistrust (Interview 17). It seemed to me that he had a naïve imagination about marriage as a safe heaven, lacked negotiating skills to practice safer sex and was in general very embarrassed while talking about sexual matters.

The problem of negotiating safer sex was apparent in all of my interviews. Most of the time people with disabilities, themselves experienced it as difficult to negotiate protection during sexual activities because there was the threat of losing their partner. Caregivers have reflected on this in a similar way. The loss would often be an emotional as well as a financial one, and so women with disabilities did not even discuss safer sex with their partner. As the quotation at the beginning of this sub-chapter illustrates, the two deaf women did not see themselves in any position to ask for safer sex. Their boyfriends chose not to use condoms and out of "respect" they did not question this (Interview 1, 2). As Tilloston noted in this context discussing HIV and condoms may mean destabilising intimate relationships (Tillotson & Maharaj, 2001, p. 89) and is therefore avoided.

Particularly for people with learning disabilities the lack of knowledge about sex and behaviour towards the other sex leads to unsafe practices. A person who has not learnt how to deal with the other sex and the circumstances under which sexual activity is appropriate, might confuse sex as a means to acquire attention. Take note of the following example:

It is like a tavern, where there were men. So she wanted somebody to make love to her. One day she came in the morning. She was carrying her panties in her bag and: ´Where do you come from?´… ´You must know, I'm old now, I need man. (laughing) And I don't have a boyfriend, I don't have a girlfriend´ So they are very open sexually. (Interview 1, provincial manager of DPSA)

The desperation for attention is often confused with the desire for sexual encounters. It is very questionable if the person in this example was happier this way and would not be better off if she had learnt how to form a long term relationship with a man. She had not learnt to distinguish her own sexual desire from her need to be loved. A boyfriend, if she would have been allowed to have one, would probably have made her happier and her later infection with HIV could have been avoided.

In addition to the controversial subject of condoms, people with disabilities have developed other strategies to protect themselves. Realising that male or even female condoms do not work for some of them, people with physical disabilities choose to either have only one partner or not to be involved with anyone at all (Interview 1, 5, 17). To avoid abuse one teenager reported that she rejected her own father, who had abused her. She lived with her aunt's family and refused to even greet her father.

Another way of protecting oneself is to use the influence of the spiritual or magical world. People might go to a traditional healer "Nyanga" and collect medicine to protect their house from HIV. This is connected to the notion that HIV is sent through witchcraft and that through the protective medicine the witch will experience the consequences of his/her own doing. The necessity to negotiate safer sex is in this case transferred into the magical world.

7.4 CONCLUSIONS

The involvement in and access to prevention, diagnostic and care programmes is very low for people with disabilities. Some of the obvious barriers to access are costs and transport options[25] as well as physical barriers on streets and buildings (see chapter 4). Another obstacle might be the negative attitudes towards disability and

[25] In KZN there are very few buses available that can transport people with disabilities and taxis have to be used. Taxi drivers and their passengers are not always very helpful in accommodating people with disabilities.

the working conditions under which public servants and here, in particular, teachers and nurses have to work. Under the ´rationing´ aspect this might have increased the exclusion of people with disabilities from services. In addition to this, disability and HIV/AIDS are highly stigmatised phenomena and it is therefore not surprising that people with disabilities are less likely to profit from prevention campaigns, diagnostics and treatment. As a result of presumptions, taboos and a rationed care system, people with disability are less likely to participate in VTC and as a result they are less likely to profit from treatment.

On an individual level disability provides an extra complication in the already complex and difficult field of sexuality. Especially teenagers experience the contradicting norms and values as confusing. In addition to this disability intervenes within everyday life as well as with the kind of relationships that a person can encounter. As a result it is even more difficult for people with disability to practice safe sex and protect themselves from HIV infection. Often sexually exploited, financially dependent and lacking sexual knowledge they are more vulnerable to HIV infection. It is especially women and girls with disability that carry this double burden.

On the whole people with disabilities find themselves in a very complex situation particularly in regard to protecting themselves from a HIV-infection. As it was described in the previous chapters on an microcultural level Subjective Theories about abnormalities and the barriers a person with disability experiences determines the reaction from and interaction with their peers and the specific living conditions the person finds him/herself in (see chapter 4 and 5 as well as the diagram below).

The diagram below (7.1) illustrates how reactions, interactions and living conditions influence the person's participation in society and with this also their sexual relationships and access to knowledge about protective behaviour, protection from abuse and treatment opportunities. Stigmatisation and neglect all too often restrict a person's participation.

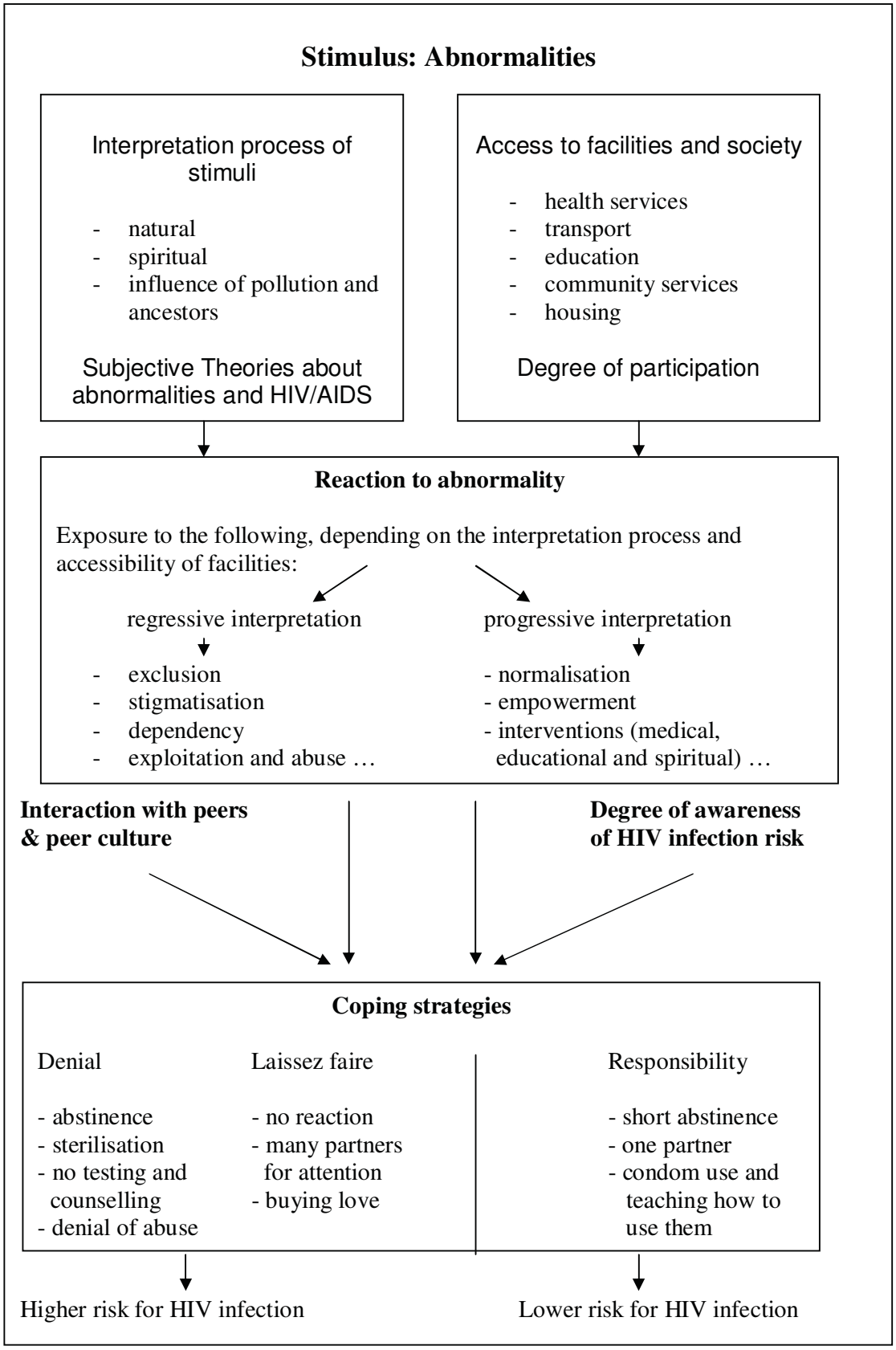


Diagram 7-1 Coping strategies to avoid HIV/AIDS infections

A person that is seen as a curse or as useless and unattractive has difficulties in finding a partner. A person that is seen as being less worthy becomes an easy target and will more likely fall victim to rape. This is particularly the case when the offenders Subjective Theory about the disability has built up the notion that the disabled person can “clean” him/herself from HIV through sexual intercourse. The notion (Social Representation) that people with disabilities and here particularly woman should “count themselves lucky”, “are asking for it” or just “don’t mind” adds to their sexual vulnerability and exposure to HIV. Their placement at the edge of a society that still treats sex as a taboo and the fact that even ‘normal’ people battle to negotiate safer sexual practices, makes this, for people with disability, almost impossible. Only the enlightened and empowered individual finds his or her way out of this dilemma.

People with disability and their caregivers are however aware of the fact that people with disabilities are vulnerable and have developed different coping strategies while dealing with the matter. On an individual level, as the diagram above shows, I was able to identify three major themes as coping strategies for this problem. Caregivers and parents may choose to completely deny the sexual development of their offspring, as described in chapter 7.2. Others might choose the contrary approach and help educate their sons and daughters about their sexuality (chapter 7.3). Again others might not take any notice at all and leave matters as they are. The latter approach usually leaves the person with the disability without any guidance and free to behave as they please. As a result of this, looking for attention and sexual acts become confused and people might develop high risk sexual behaviour.

One needs to understand that the factors that influence the sexual behaviour of people with disabilities and their able-bodied peers are diverse. The interpretation process of disability determines the reaction to an abnormal feature and the behaviour that the person with the disability will show him/herself. The reaction to one’s environment, the person’s personal coping strategies and the opportunities provided (access) by society, determine a person’s grade of participation or exclusion. This also influences the exposure to stigmatisation, exploitation and abuse, the degree of dependency as well as the access to equal opportunities under normalised and empowered circumstances. The specific life situation resulting out of this, in combination with the interactions within the peer group and the degree of

HIV/AIDS awareness, will determine how a person with disability is able to protect him/herself from HIV infections.

In conclusion there is no simple answer to the complex situation in which people with disabilities find themselves. It should however become apparent that awareness programmes, a stricter judicial system and access to facilities will not reduce the HIV infection risk alone. Furthermore, notions about disability have to be altered, sexuality as such has to be addressed more progressively, positive non sexual encounters between boys and girls have to be provided and safer sex needs to be promoted.

8 SUMMARY – PROSPECTS FOR TRANSFORMATION

In the introduction to this thesis I stated my goals and objectives in conducting this research. Foremost amongst these was the desire to illuminate some of the more silent and commonly-held notions relating to disability and HIV/AIDS. Furthermore I tried to ´unwrap´ the complicated interrelations between these notions so as to make the reader understand how the conceptualisation of disability increases exposure to HIV. For this purpose I studied concepts, notions and imaginations of disability and HIV/AIDS as well as historical grown settings and approaches to both phenomena. While using McElroys and Jewzeskies (2000, p. 192) model I analysed the themes surrounding disability and HIV/AIDS on a macrocultural, microcultural and individual level (appendix 12). To round off my thesis, I would like to underline a few points by briefly recapitulating the implications of my findings in relation to current anthropological theories. In addition to this I would also like to summarize the practical relevance of my work in relation to the three levels suggested by McElroy and Jewzeski.

It is nothing new to say that the signs and symptoms that define disability vary culturally (Dederich, 2007; Neubert & Cloerkes, 1994). As a normative framework for decision-making, culture is an integral part in defining abnormalities and choosing appropriate treatment and behaviour. Criteria of health, disease and disability usually include utilitarian components such as the ability to provide for a family and to fulfil expected roles. In an African context the spiritual world has to be added. As I have shown in chapter 5, the cultural construction and representations of disease and disability are not intra-culturally uniform, as Cloerkes (1994, p. 87) found 20 years ago. People more or less develop their own Subjective Theories about disease and disability based on their knowledge, culture and need for explanation. “Culture” in this context means more than traditions as we hardly find “pure” cultures in the world anymore. Progressively culture should be understood as something dynamic that changes and has to change in accordance to meeting the demands of an ever changing environment (Geertz, 1983). Culture in this context is influenced by historical traditions as well as local and international developments. In the time of globalisation the influence of the latter is eminent and forces Africa, in particular, to modernise its society. It may therefore not be surprising that in the given hybrid

“culture” people come into contact with different explanation models and develop their own Subjective Theories about diseases and disabilities. In fact they are predestined to become objects of everyday theories, as they are visible and will be experienced by everyone.

The experience of disease and disability has been studied on several analytical levels: (see introduction and appendix 12) the individual, the microcultural and the macrocultural. As a first step I will try to incorporate my findings into these 3 levels while I will try to identify strategies that could be implemented to change the situation as a second step.

Individual level

Recognising the wide spectrum of disability concepts and the fact that professional criteria differ markedly from Subjective Theories, I identified three major approaches that people choose while explaining disease or abnormality. My research results indicate that diseases or abnormities were understood to be either of natural or spiritual origin, or a combination of both. A considerable influence was also attributed to the degree of personal protection (e.g. through ancestors) or the degree and type of pollution (e.g. through death). Even though I identify categories of interpreting abnormality, I would like it to be understood that personal theory building is a process of ´picking and choosing´ what makes sense for an individual in a particular historical situation. This process is based on personal knowledge, notions and attitudes. The Subjective Theories of my participants mirrored a hybrid between tradition and modernisation as many people in KwaZulu-Natal are influenced by the traditional as well as the modern way of life.

The individual experience of disability differed between my participants. While some experienced the attitudes of others, a lack of respect and access as a dominant characteristic of their life with disability, others progressively saw their disability as a challenge which they would try to overcome. I noticed a particular difference of disability experience between the genders. While most men focused on regaining respect and status in their communities, women were more worried about access to health services, education and transport and their vulnerability, particularly to abuse.

In the context of HIV/AIDS I have to underline the concept of pollution. This concept is seen by a number of anthropologist as influential to the spread of HIV and the victimising of women (Harrison et al., 2001; Jewkes & Wood, 1999; Leclerc-Madlala, 1999; Schapera, 1946). The notion of pollution is deeply embedded into the Zulu culture and implies that illness is mainly a woman's business and as Leclerc-Madlala (1999, p. 130) comments, women are therefore seen as responsible for spreading HIV/AIDS. The concept surrounding women and disease is also a dualistic one, as a "special woman" like a virgin can be subjected to purification rites. A woman with disability, in this context, might also be perceived as pure and "clean", when the interpreting person assumes that she is not sexually active and thus a virgin. In combination with the notion that sexual intercourse with "pure", "clean" individuals can cure AIDS and is safe, people with disability as well as children become prime victims of "cleaning rituals" (purification). As these rituals are, most of the time, of a sexual nature children, virgins and people with disabilities have become prime victims of sexual abuse. This current mythical discourse needs to be interrupted and challenged, so the rights of children, women and people with disability can be protected. Changes on the other two levels might be able to contribute to a change in Subjective Theories about disease and HIV/AIDS, as Subjective Theories feed off Social Representations that can be explored on a microcultural level.

Microcultural level

Medical sociologists, social psychologists and anthropologists have long recognised that beyond the clinical domain of individual experience lies the psychosocial microcultural realm of relationships transformed by illness, disease or abnormalities. Disability experience and Subjective Theories about disability are influenced by gender, age, class, education and ethnicity (Albrecht, Seelman, & Bury, 2001; Helman, 1994). These aspects will influence the threshold of noticing an abnormality as such, as well as the way a person seeks for or offers information, treatment, care and assistance.

HIV/AIDS as well as the phenomenon of disability, illustrate that they are not only a self experience but also a social and community experience. Both phenomena can be subject to concepts of moral responsibility and in such a case are highly

stigmatised. In Esses' (1994) comparisons of people with depressions, HIV and amputations, and in Room's (2001) comparison of people with disabilities and addictions, the attitude of the peer population depended on the interpretation of the abnormality. In Esses' study people showed more negative attitudes towards people with depression or AIDS than they did towards amputees (Esses, 1994, p. 50). Similarly, in Room's study, disabilities caused by accidents were attributed with less negative stigma than drug addiction or disability seen as caused by a curse from god (Room et al., 2001, p. 265). The element of control was crucial in both studies. Similarly, in my study, people would show more negative attitudes towards people with disability, rape victims or HIV positive people if the person could be made responsible for the "misfortune", by either not following traditional custom, behaving immorally, being seen as cursed and so on. Here I would like to compare my findings to Goffman (1963) who interpreted disease and disability as leading to interactions profoundly marked by stigma that is spoiling or discrediting identity. Stigmatisation would have a triple effect if a person was a woman, HIV positive and had a disability. This marginalizes them within society and makes them very vulnerable.

Nevertheless some people with disability and their caregivers have found ways in which to speak out against their stigmatisation and develop coping strategies and positive identities in spite of (or because of) negative attitudes. My data shows that some people, although their stigma clearly deprived and disturbed them during their childhood or just after an accident or disease, had developed a positive body image after a certain period of time. This led to the development of progressive coping strategies which often included a strong support system through disability organisations and programmes (e.g. DPSA, DICSA or CBR). It is interesting to note that these people who developed positive images of themselves or their offspring, were often those people that also practised progressive sexual education and were not (anymore) involved in risky sexual activities. Thus this positive self image and empowerment decreased their exposure to HIV.

Macrocultural level

In this context I would like to press the point that HIV/AIDS has not, surprisingly and inexplicably, suddenly arrived at the African doorstep. The epidemic has not evolved suddenly like a volcanic eruption or tidal wave and it is not to be confused with any other natural catastrophic event. I have tried to show that the HIV/AIDS epidemic is a result of the African development over the last two hundred years, with tribal warfare and the political systems of colonialism as well as apartheid having prepared the ´field´ for the HIV virus to spread fast and effectively. The fast modernisation of the African state has added to this problem. The traditional way of life has been rapidly distorted and little effort, if any at all, has been given to replace the "old" social system with a "new" one. Swarms of men have been isolated from their families through the migrant worker system and the homeland policies. In the cultural "ruins", women are left behind and have to raise children by themselves. It is not surprising that men began to have girlfriends in the cities and women, for their part, have boyfriends to support their lifestyles at home. Families in which both the father and the mother are always present have become rare. The often described "African" promiscuity is in this sense not only a result of "old" traditions, but also a result of the continuous destruction of African social structures. In these new relationships condoms are not used as they are a sign of mistrust. One can almost get the impression that women and men live in different worlds and that they only come together to exchange the deadly virus, while nobody really talks about sexual topics and the cause of HIV is still mystified. At this point I would like disagree with Gronemeyer (2002, p. 109), who presses the point that through the "HIV/AIDS awareness era" in Africa the body has become a technical object while the spiritual side of a relationship has been forgotten about. I would like to question this "forgotten" spiritual relationship between men and woman in Africa who always had material reasons for getting married. I think we are misled here, with the romantic notion that in the past, relationships between the sexes have been of a purely spiritual nature. A fact in this matter is that in the past the African society had an existing social structure, which has now fallen apart.

What was once the African extended family is now a ruin (Mutwa, 2003). Prostitution, promiscuity, crime and rape have become a daily phenomena with which every

South African has to deal with to some extent. The Elite get infected during their business trips, students in boarding establishments, pupils by their teachers and peers and during deadly adventures on the weekends. The peak of the social destruction is the chauvinistic culture in which KwaZulu-Natal is still entrenched but cannot afford in the face of the epidemic. Men overpower women and take advantage of them while women live with the impression that they have to be obedient and quite. In the face of such social problems people with disabilities simply ´fall over the edge´.

South Africa's policies in regard to disability are very progressive but little implemented, while the policies on HIV/AIDS are very contradictory. In the case of HIV/AIDS a desperate attempt to find an "African" solution is still apparent and many previous writers encourage Africans to find their own solution[26]. This "African" solution however does not focus on the social-cultural construction of AIDS and therefore is not effective. In contrast to Europe, Africa was confronted with the AIDS emergency before it began its sexual revolution and emancipation process. South Africa needs therefore to fast forward its development in regard to gender issues before HIV/AIDS programmes can become effective.

People with disabilities

Now, where does that leave people with disabilities? As I have attempted to demonstrate, people with disability in KwaZulu-Natal and probably in the whole of South African society, are particularly vulnerable to abuse and exploitation. In addition to this the information and education they receive about their rights, rehabilitation and HIV/AIDS is insufficient, therefore HIV/AIDS intervention and awareness programmes need to be altered. People with disability are often seen in need of care and receive little HIV/AIDS related intervention (Ntuli, 2004). They are therefore less informed and often disadvantaged when it comes to sexual decision making. As Mazibuke (1989, p. 108) reports, in many cases children with disabilities still do not, or have only delayed access to education as there are few facilities that

[26] It is however questionable why writers do this. The HIV/AIDS epidemic is so overwhelming and so many prevention approaches seem to have failed for different reasons that one can not deny the impression that these writers maybe just are not able to come up with an alternative themselves. It seems to me a romantic notion that Africans can find a solution to their problem themselves, when the epidemic has such diverse patterns and colonial influence in the past as well as current modernisation seems to have stirred up the epidemic.

can cater for them and often schools have certain entry levels (like being able to go to the toilet or being able to walk). Those children and youngsters that go to special schools are often not exposed to HIV/AIDS awareness, either because caregivers and teachers feel that they do not need it or because material and teaching methods do not meet the special needs of those pupils. The denial of access to education and sexual knowledge in particular, limits the prospects for a successful life in every context, so it also increases the risk of getting infected with HIV. Groce already estimated in 2003, that people with disabilities might be more at risk of getting infected with the virus and my research supports this prediction. On the contrary to Blumberg's and Dickey's research in the USA (Blumberg & Dickey, 2003), people with disability in KZN are less likely to be reported with a positive HIV status and are also less likely to be tested for HIV. The reason is that they generally receive less medical care and attention, or a disease might be seen as another magical misfortune and a diviner is approached rather than the local clinic. The consequences are that they are less likely to be treated in the case of an HIV infection as well as for other STDs.

Prospects for transformation

The mystification of disability as well as HIV/AIDS has created a massive field of speculation, where people choose the most arbitrary prevention and treatment strategies. McElroy and Jezewski mention the concept of "cultural brokering" as a useful and heuristic approach to link different levels of health experiences. They define cultural brokering as "the act of bridging, linking or mediating between groups or persons of different cultural systems for the purpose of reducing conflict or producing change" (McElroy & Jezewski, 2000, p. 193). This "bridging" and "mediating" needs to be applied on all three levels so that Social Representations and with this Subjective Theories about disability as well as HIV/AIDS can change.

On an individual level, people with disability need to understand that their disability is also a social construction and not only a personal issue. I argue that the social concept of disability helps to de-individualise disability and removes the burden of personal guilt or stigma, while the affected person learns to understand the social determinants of their devalued status. In this context improved access to knowledge

and education (informal and formal) will be an important determinant to overcome the devalued status. In the process of moving to a more social paradigm, people with disabilities themselves play a crucial role and have to make an extended effort to help their able-bodied peers to overcome difficulties in interacting and understanding disability (Albrecht et al., 2001, p. 360). In the context of HIV/AIDS it is also important that people with disabilities are included in HIV/AIDS prevention and treatment programmes. A promising development, in this regard, is the material developed by the African Union of the Blind, which has recently released a “train the trainer manual” for the blind (AFUB, 2008b) or the South African disability sector report on HIV/AIDS and disability which identifies issues and possible approaches.(South African National AIDS Council (SANAC), 2008).

At the microcultural level we can look at the local as well as provincial level. South Africa has undertaken attempts to transfer more power into the hands of local stakeholders and authorities as well as decentralise systems. In the health sector this has not been effective enough as yet (Veenstra, 2007). In addition to this the co-ordination of different programmes and initiatives seems to be unutilised. When asked about CBR most nurses and hospital staff did not even know what this was and thus collaboration was not seen as necessary. From their perspective CBR workers often complained that they had difficulties co-operating with the health sector. A major opportunity to initiate this collaboration would be to combine the efforts of the HCBC and CBR programmes. Both systems work with local personnel and at grassroot level. While the former deals with the ill the latter approaches disabled people. Facing human resource problems in both systems, one should explore if both could not collaborate better. This collaboration could theoretically even operate with identical personnel. The HCBC system would acquire valuable human resources while CBR workers could be rewarded financially. The main obstacle would be to train the CBR workers in basic medical terms, which should be possible to achieve. These CBR and health workers could also help to demystify disability and raise awareness against abuse.

On a provincial level hospitals, in particular, have already received a certain amount of self governance, except in the area of ARV rollout. The latter is hampered as there is not as yet enough expertise in the field and control from top level still seems to be

In the context of changing Social Representations about disability and HIV/AIDS I would like to refer back to previous anthropologists and HIV/AIDS researchers (Leclerc - Madlala, 1999; Whiteside, Mattes, & Willan, 2002), who have pressed the point that people need to be liberated from the "naïve and mythological stages of consciousness". These researchers recommend an "education of liberation" as described by Paulo Freire (1972) as a valuable approach. The advantage of this type of pedagogic, is its adaptability to different cultural realities. In Freire's approach, things are named as they are and taboos are broken on purpose. The "invisible" becomes visible. This practice is needed to overcome old habits and myths, without destroying valuable cultural traditions and treatment[28]. Incidentally, people will be educated by their peers, an approach that has been internationally recognised as an important indicator for success. This also reinforces inclusion of marginalized groups into mainstream settings. In addition to this "education of liberation" is always a community based approach and this is an opportunity to draw connections to already existing networks like the Community Based Rehabilitation projects (CBR) in KwaZulu-Natal. In this sense people can be "liberated" so that they can make informed decisions about sexuality, HIVAIDS and disability. However all these efforts would be doomed if these interventions do not aim at a change in society as a whole. Social-cultural factors play an important role in the spread of HIV/AIDS. This also applies to the phenomenon of disability. Only social change can influence the behaviour patterns people have developed towards sexuality, HIV/AIDS and disability. This is crucial so that interventions can have a long term and sustainable impact on the current HIV crisis.

Taking the previous thought into account, cultural stereotypes that claim 'tradition' as their justification, need to be challenged. Tradition in South Africa is all too often a silencing argument, where people feel that their cultural heritage either cannot or should not be changed. I particularly want to name the phenomenon of "isoka", "lobola", multiple partners, virginity testing, sexual violence and common ´purification´ practices as well as the conceptualisation of respect. Without a conscious alteration of these phenomena, there is not much value in liberating some people while leaving others out. Social change needs to affect the whole society and not just a part of it during a certain intervention in time. In this context I would like to extend Leclerc-

[28] Refer here back to chapter 5. It showed also the strengths and advantages of traditional healing.

Madlala's (1999, p. 245) view and press the point that the much needed change has to go far beyond the educational sector. KwaZulu-Natal's society as a whole, has to be altered on all levels of society. To the extent that sexual behaviour is nestled within a complex range of psycho-social processes the social change has to be complex and broad. Progressive and comprehensive programmes from other African countries can be used as a model, for instance the project of the "Raising Voices" in Uganda (see www.raisingvoices.org). With regard to this statement I just want to reiterate the fact that there is little value in telling a man not to abuse women, if violence against women has become so embedded in local culture that it is no longer even perceived as abuse. The minds of women and men, disabled or able bodied, need to be drawn into a new consciousness.

In the light of the current HIV/AIDS crisis, it will not be enough to simply understand internalised images that inform the meanings people attach to HIV/AIDS and disability or to simply improve access to education and health services. I strongly believe that the notions about disability and HIV/AIDS must be incorporated into an intervention strategy. This strategy, however, needs to then be incorporated into attempts to drastically change South Africa's social structure while creating more tolerance and empowerment of marginalized groups like women and people with disabilities. In this context, sexual stereotypes need to be challenged while at the same time sexual concepts and common practises need to be revolutionised. The focus should however lay within conceptualising healthy relationships and reconstructing the concepts of masculinity in a positive way.

9 FOR THEMBELIHLE[29] – A PERSONAL REFLECTION

Thembelihle is a little girl growing up in rural KwaZulu-Natal. She is not the type of girl who will one day skip happily through the fields of her forefathers. In fact she might never walk at all. Thembelihle is severely disabled as a result of her premature birth. She spends most of her days lying on the couch in a little cottage that her foster mom occupies. Maybe she is looking at her surroundings, maybe she is studying a little spider web at the top of the roof, but how much she perceives is a secret to us all. Thembelihle is 3 years old and maybe she is proud, now that she can at least hold her own head. In some ways she is lucky. Unlike other orphans she has found a home and a caring foster mom, who does everything to develop her little muscles. Her foster mom sings for her while doing her physiotherapeutic exercises. It is this singing that she enjoys the most.

This Thesis was dedicated to Thembelihle as her case reflects the story of HIV/AIDS in KwaZulu-Natal and possibly in South Africa. Neither Thembelihle nor her mother were ever given a fair chance in life. Thembelihle´s grandmother died of an AIDS related disease leaving Thembelihle's mother behind at the age of twelve or thirteen. Left all on her own, Thembelihle´s mother had to look after herself and her siblings. Life must have been tough for these children and particularly for Thembelihle's mother, who was no more than a child herself and the head of the household at the same time. What chance did she have and how was she supposed to support herself and her siblings? It was probably then that men took advantage of the girl and infected her with HIV. A further result of the abuse was that she soon became pregnant with Thembelihle. At this time Thembelihle´s mother was already growing weak as a result of the virus and malnutrition. She gave birth to Thembelihle when she was only just in the sevens month of her pregnancy. The father of her child was nowhere to be seen. She died three days later at the age of fourteen. Her baby was left in a pit latrine near the hospital. There, Thembelihle was found and later brought to the orphanage, where she now lives. At first it did not look as if she would survive for very long; her immune system was very weak as a result of the HIV infection. The people at the orphanage took good care of her and soon her condition improved. It

[29] Name has been changed to protect Thembelihle's identity. Thembe means hope in Zulu.

was here at the orphanage that she found hope, despite the fact that the severe disability and the HIV infection will persist to be a burden for the rest of her life.

The story of Thembelihle, in closing this thesis, provides an ethical as well as personal reflection. Qualitative research is usually chosen to avoid the reduction of the respondents to the status of an object (David & Sutton, 2004, p. 81). The researcher will try to present the ´respondents´ story from ´their (respondents) point of view´. This however, as Becker argues, will often be taken as advocating rather than simply representing the topic (Becker 1967, p. 240). In the case of researching two phenomena, disability and HIV/AIDS, which are both highly stigmatised, it was not possible to be completely free of bias. This thesis is therefore written to give people with disability a voice and an opportunity to bring their case forward. It is also a critical reflection of society in KwaZulu-Natal. The attempt was made to understand this society from within, in other words from an emic perspective, without compromising basic ethical standards and personal values. The thesis might not always reflect popular opinion in KwaZulu-Natal. Nevertheless it reflects the ´truth´ as it was told by my participants and the experiences I had during three years of research. While as a qualitative contribution this thesis might be accused of bias in favour of those that were researched[30] (Hammersley 2000), the research was however conducted as objectively as possible and the results have been presented in a truthful way.

Thembelihle´s story is true. Even though we might not like it, her story is not a rare case but a representation of the destruction within KZN's society. It has to remind us that we have not done enough to change our world for the better and that the struggle in South Africa is far from over. It also needs to reinforce in us, that besides all the obstacles, there is hope and that this hope lies within the African community itself. It lies within all those people, of whatever race and nationality, that open their eyes and hearts and are prepared to change themselves and give a chance to others. The old African "gogo"[31] can be heard saying that "ubuntu[32] is dead", but maybe this old African way of life needs a modern revival in the hearts of all South Africans.

[30] I refer here to people with disability and not to people in KwaZulu-Natal in general.
[31] Gogo – Zulu for an old woman or granny
[32] Zulu saying for helping, respecting and supporting each other.

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APPENDICES

APPENDIX 1

Definitions and Zulu-vocabulary

General definitions

abnormality	- a certain feature that deviates from what is culturally perceived as being the norm
African	- a person of black African descent or something belonging to his/her cultural background
antiretroviral	- group of drugs that stop the HIV reapplication, also abbreviated as ARV
biomedical	- approach that uses modern science, biology and medicine
disease	- disorder of structure or function in a human, that is not of a permanent nature
disability	- a condition that limits a persons activity often caused through a physical, sensorial, psychological or intellectual impairment
emic	- with an insider view
ethic	- with an outsider view
healer	- a person that prescribes treatments to improve peoples health and treats diseases
herbalist	- a traditional healer, that mainly focuses on the treatment of bodily related diseases through the use of herbs and animal by-products
modern	- after the scientific and industrial revolution, being up to date in techniques and equipment
Nevirapine	- a type of ARV, that is given to pregnant woman to reduce the risk of HIV infection of the child
practitioner	- traditional healer or medical doctor
pre-modern	- before the scientific and industrial revolution
primitive	- historical term to describe pre-modern cultures
ritual	- religious or solemn ceremony involving a series of actions performed according to a prescribed order
sangoma	- spiritual healer that can use his power in both a useful or destructive way
scientific	- relating to or based on science

traditional	- transfer of customs and beliefs from one generation to the next
western	- living in, coming from or characteristic for ´the West´, which is often associated with Europe
Zulu-speaking	- all people, who have Zulu as their first language
Zulu-cosmology	- belief system of Zulu-speaking people, that forms their traditional custom and way of live

Zulu vocabulary

abathandazi	- faith healer
amaphansi	- ancestors
ilabolo	- bridal gift or money
imikhondo	- track, trail
impilo	- well being
inyanga	- herbalist, traditional healer
izangoma	- diviner
izinyanga	- herbalist
sangoma	- spiritual healer (sometimes also used and confused with the word witchdoctor)
ubuthakathi	- witchcraft or sorcery
ufuza	- a disease or disability that runs in certain families
ukuthwasa	- initiating process to become a sangoma
umnyama	- darkness, commonly known as pollution
umuthi	- medicine
umuthi omnyama	- black/dark medicine
umuthi omhlope	- white medicine

APPENDIX 2

Map of South Africa and provinces

Source: **www.c.-r.-org** **(9.01.2008)**

APPENDIX 3

Map of KZN and municipalities

Source: **www.kznhealth.gov.za** **(9.01.2008)**

APPENDIX 4

History of AIDS policy making in South Africa

1990
conference on health & welfare in Mozambique / ANC is part (N. Nattress 2004, p 42)
→ 0.8%[1] of women were found HIV positive in South Africa

1992
conference on AIDS uniting the ANC and the old government's department of health →
an umbrella body was tasked with the developing a coordinated response to AIDS →
"AIDS-Plan" was developed, it was very progressive at this time (N. Nattress 2004, p 43)

The plan wasn't supported by political activist & trade union. One reason might be to ease at this time, the assimilation of returning exiles, many of whom were returning from high HIV-prevalence areas.
With other words: The early transitional period had not a conductive environment for addressing AIDS.

1994
AIDS became a "Presidential Lead project" with preferential access to funds → a national AIDS Programme Director was appointed in December 94(at the health department not direct at the president)
→ Initiatives lured away from the outlined AIDS-plan and lost strength and focus
→ 7,6% prevalence rate based on antenatal testing

1995
Savafina II (p. 45) a stage show fitting the musical Sarafina with anti-AIDS messages was produced (14.2 Mill R from EU)
process was rushed and taken without experts, government failed to get permission to spend this money on the project, script was unsuccessful and confusing
→ Scandal and failure

1996
International Conference for People Living with HIV / AIDS was held in South Africa. Mbeki and the health minister acknowledged the seriousness of the epidemic
→ 14,3 % prevalence rate based on antenatal testing

1997
Announcement of the development of "Virodene" as an in SA developed treatment for AIDS
In reality it was an in the cancer treatment failed medicament, which contained highly toxic industrial solvents.

1998
Evidence becomes available on the benefits of AZT (Zidovudine) to prevent MTCT, but government will not make it available because of concerns over affordability and toxicity.

[1] All prevalence rates are taken from the Avert study: www.avert.org/safricastats.htm in June 2006

The pressure group Treatment Action Campain (TAC) was started to advocate for the rights of people living with HIV/AIDS and demanded a national treatment plan
→ 22,9% prevalence rate based on antenatal testing

1999
government policy making became centralised and the AIDS debate influenced by Mbeki and his ill-advised views
→ health minister Dlamini-Zuma (was on the conference in 1990 & 1992) refused to make Zidovudine (AZT) available for MTCTP → argued it is unaffordable
→ Western Cape provincial government (not ANC) ignored the national policy and started pilot projects on poor communities with MTCTP (together with MFS)

→ Tshabalala-Msimag (was on the conference in 1990 & 1992) became minister of health → president Mbeki urges the council members to find out where "the truth lies" and to consult the "huge volume of literature" available in the internet (e.g. virusmyth.com)
→ Tshabalala-Msimang says AZT weakens the immune-system, leads to mutations and birth defects. She also downgraded established scientific opinion as just one view among many.

2000
AIDS policy making was characterised by the political marginalisation of established scientific information and modes of discourse. At the International AIDS conference in Durban, the South African president Thabo Mbeki said that AIDS was a disease caused by poverty, not by HIV.

In Januar 2000 the South African National AIDS Counsel (SANAC) was launched →
no experts or high-profile civil society groups were invited (N. Nattress 2004, p. 50)
Shortly after Mbeki creates the "Presidential international panel of scientists of HIV in Africa" that contained conventional scientist and dissidents, who believed that AIDS was caused by poverty rather than HIV
October 2000 Mbeki announced that he was withdrawing from the public debate.
→ 24,5% prevalence rate based on antenatal testing

2001
April 2001 the cabinet releases the statement to the effect that HIV causes AIDS (N. Nattress 2004, p. 54)

2002
Richard Feachen from the Global Fund evaluates SANAC as "not yet functional", "does not meet often enough to do concrete work"
(Mail and Guardian 11-17 of April 2003)

On the Durban AIDS conference the coordinators and colleagues made a public plea for Mbeki to keep clear of the scientific debates. → The answer was a harsh critic from 3 ministers saying that these people were frontline troops of the pharmaceutical industry (Nattress 2004, p. 51 / 52)

Even so Mbeki had backed out of the debates, is former dispute hat still an major effect on the AIDS policies through the coming years (Sunday Independent 9 Aug. 2003)
→ 26,5% prevalence rate based on antenatal testing

2003
AIDS policy-debates focussed on feasibility, affordability and implementation of a national treatment plan
February 2003 the Minister of Health refused to sign the "framework agreement"
(Mail and Guardian 28 February – 6 March 2003, 15 –21 August 2003; Business Days 19.March 2003)

⟶ South Africa developed a "moral economy of triage" to address the AIDS issue (N. Nattress 2004. p 57) ⟶ The government wants to allocate money rather to prevention than treatment, forgetting that AIDS isn't comparable with a warlike situation and that HAART would have an tremendous preventive impact.

The Minister of Health appoints controversial dissident as her nutritional adviser and attacks KZN for having put successful proposal to the Global Fund to support ART roll out.

President Thabo Mbeki denies in an interview with the Washington Post to have ever known anyone who has died of AIDS.

2004
MTCTP becomes available, but isn't used to it's full capacity as VCT doesn't approach enough people yet
⟶ 29,7% prevalence rate based on antenatal testing

The Minister of health labels ARV´s as toxic after consultation with the German vitamin entrepreneur Mathias Rath.

2005
ARV (Antiretroviral medicine) are available in pilot projects and later in hospitals around the country, but doesn't reach enough people yet
⟶ 30.2% prevalence rate based on antenatal testing

HAART is being discussed

The Rath Fooundation claims that vitamins can cure AIDS and that TAC is a forefront of the Pharma Industry. The Heath minister Tshabala-Misinmag does not distance herself from this vitamin entrepreneur (Mercury 28.05.2005)

2006
The head of the Moral Regeneration Movement; chairman of the South African National Aids Council; And Deputy President of the ANC Jacob Zuma, had voluntarily unprotected sex with a HIV-positive woman and publicly announced that he took a shower after the sexual intercourse to reduce his risk of getting infected (Jacob Zuma Rape trail 2006)

Health Minister Manto Tshabalala-Msimang presented South Africa at the HIV/AIDS conference in Toronto with a "salad stand" insisting that vitamins, garlic and beetroot are an alternative for ARV treatment in the fight against AIDS. 60 international experts on HIV/AIDS call for the resignation of Tshabalala Msimang.

The Mecicines Control Council impounds a shipment of Raths Healths Foundations products which contain Schedule Two substances. The shipment is released by order of the Department of Health.

November 2006: The government sends a signal out that messages about nutrition's from Health Minister Manto Tshabalala-Msinmang are "demanding" saying it has the duty to "remove all the confusion". Deputy Health Minister Madlala-Routledge takes a public stand for ARV treatment. (The Mercury 1.11.2006, Sunday Tribune 24.12.2006)

⟶ 29,1 % prevalence rate based on antenatal testing

⟶ two percent drop of HIV infections in the under 20 group

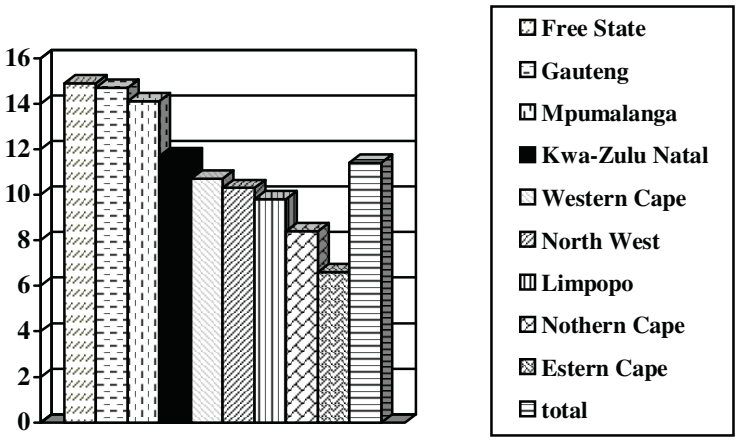
2007

Nationwide strike in the public sector in June 2007 threatens the ARV distribution and People are left without ARV and threatened to develop ARV resistant virus strains (The Mercury 13.06.2007)

Deputy Health Minister Madlala-Routledge is removed from her post.

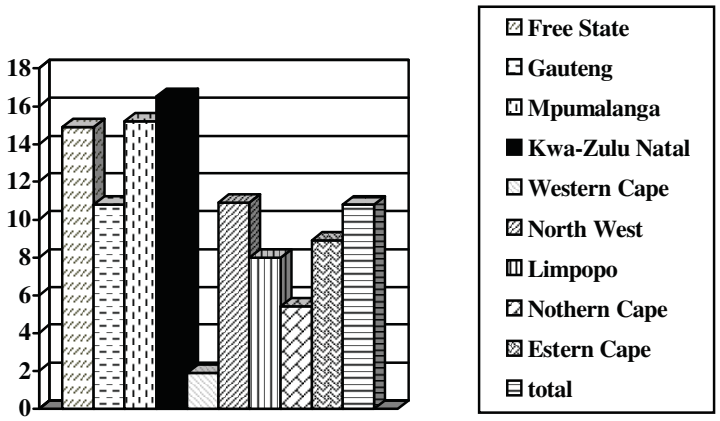
APPENDIX 5

5.1 Prevalence rate Nelson Mandela study, 2005



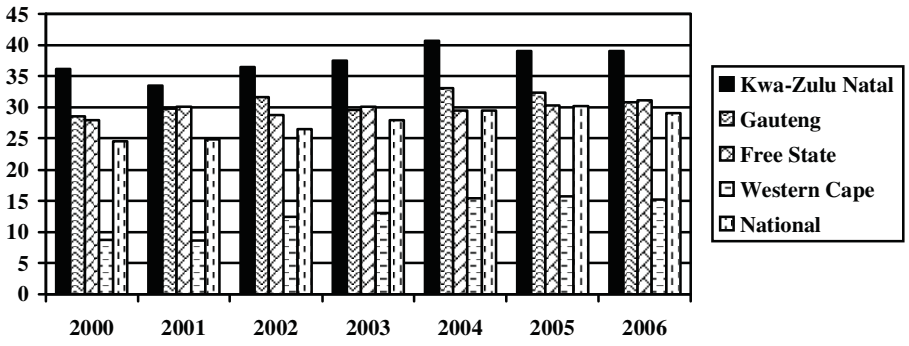
HIV prevalence rate of population, participants where volunteers of all ages and gender

5.2 Prevalence rate South African National Survey, 2005



HIV prevalence rate of population, participants where volunteers of all ages and gender

5.3 Prevalence rate South African department of health study, 2007



HIV prevalence rate of woman in public antenatal clinics

APPENDIX 6

Data from the South African Department of Health Study, 2006

Estimated HIV prevalence among antenatal clinic attendees, by province

Province	2001 prevalence %	2002 prevalence %	2003 prevalence %	2004 prevalence %	2005 prevalence %	2006 prevalence %
KwaZulu-Natal	33.5	36.5	37.5	40.7	39.1	39.1
Mpumalanga	29.2	28.6	32.6	30.8	34.8	32.1
Free State	30.1	28.8	30.1	29.5	30.3	31.1
Gauteng	29.8	31.6	29.6	33.1	32.4	30.8
North West	25.2	26.2	29.9	26.7	31.8	29.0
Eastern Cape	21.7	23.6	27.1	28.0	29.5	29.0
Limpopo	14.5	15.6	17.5	19.3	21.5	20.7
Northern Cape	15.9	15.1	16.7	17.6	18.5	15.6
Western Cape	8.6	12.4	13.1	15.4	15.7	15.2
National	24.8	26.5	27.9	29.5	30.2	29.1

Estimated HIV prevalence among antenatal clinic attendees, by age

Age group (years)	2001 prevalence %	2002 prevalence %	2003 prevalence %	2004 prevalence %	2005 prevalence %	2006 prevalence %
<20	15.4	14.8	15.8	16.1	15.9	13.7
20-24	28.4	29.1	30.3	30.8	30.6	28.0
25-29	31.4	34.5	35.4	38.5	39.5	38.7
30-34	25.6	29.5	30.9	34.4	36.4	37.0
35-39	19.3	19.8	23.4	24.5	28.0	29.6
40+	9.8	17.2	15.8	17.5	19.8	21.3

http://www.avert.org/safricastats.htm 13.06.2007

APPENDIX 7

Mortallity and causes of death in South Africa, published by Statistics South Africa May 2006

Reported deaths from all causes, 1997 to 2004

Year of death	Age (years)					Total
	0-9	10-24	25-49	50+	Unspecified	
1997	35,441	22,636	92,796	160,058	5,574	316,505
1998	41,172	25,799	114,215	178,763	5,104	365,053
1999	41,834	27,686	129,881	178,877	2,704	380,982
2000	42,802	29,463	150,149	189,118	2,204	413,736
2001	44,876	31,408	172,963	201,738	1,911	452,896
2002	50,741	34,381	200,844	211,504	2,024	499,494
2003	56,593	37,363	228,819	227,280	2,770	552,825
2004	62,212	38,054	242,066	222,231	2,925	567,488
Increase 1997-2004	76%	68%	161%	39%	-52%	79%

The influence of population growth can be removed by looking at death rates per 100,000 people, which are provided by Statistics South Africa in another report called "Adult mortality (age 15-64) based on death notification data in South Africa: 1997-2004". These data show that between 1997 and 2004, the death rate among men aged 30-39 more than doubled, while that among women aged 25-34 more than quadrupled. The changes are even more pronounced when deaths from natural causes only are examined. Over the same period there was relatively little change in the death rates among people aged over 55 and those aged 15-20. In their report, Statistics South Africa call such developments "astounding", "alarming" and "disturbing".

Source: http://www.avert.org/safricastats.htm 13.06.2007

APPENDIX 8a

HIV/AIDS burden on hospitals as a proportion of illness in health facilities

Location	Burden of HIV/AIDS as a proportion of illness in health facilities	Translation into a financial burden
United Bulawayo Hopsitals, Zimbabwe (Mudiayi et al. 1997)	7.0% of all admissions due to HIV/AIDS (1987-1994, adult medical **inpatients**) 0.5% of medical admissions due to HIV/AIDS in 1987, increasing to 18.1% in 1994. Data based on diagnosis at discharge and ICD.	
St Mary's Hospital Lacor, northern Uganda (Accorsi et al. 2001a)	1.9% of all admissions, 2.7% of inpatient bed days due to AIDS (1992-1997, paediatric **inpatients**) Data based on diagnosis at discharge and ICD.	
Three hospitals, northern Uganda (Accorsi et al. 2001b)	1.1%-1.7% of all admissions due to AIDS (1992-1998, adult **inpatients**) Data based on diagnosis at discharge and ICD.	
St Mary's Hospital, Lacor, northern Uganda (Fabiani et al. 2003)	5.5% of all admissions, 4.1% of inpatient bed days due to AIDS (1999, adult medical **inpatients**) Data based on diagnosis at discharge and ICD.	
Various hospitals (15), Western Cape, South Africa (Roux et al. 2000)	8.3% of paediatric beds occupied by HIV/AIDS patients (1999, paediatric **inpatients**) Data based on clinical diagnosis and test result where available.	
Various hospitals across KwaZulu-Natal, South Africa (KZN Department of Health 2004)	12% of admissions due to AIDS (1998-2002, all **inpatient** admissions) Data based on diagnosis at discharge and ICD.	
King Edward Hospital, KwaZulu-Natal South Africa (Mahomed et al. 2006)	8% of all admissions due to HIV/AIDS (1998-2002, all adult **inpatients**) Data based on diagnosis at discharge and ICD.	Longer **inpatient** stays for all HIV/AIDS related admissions 9.5% of financial expenditure incurred on adult inpatients due to HIV/AIDS.

Source: (Veenstra 2007)

APPENDIX 8b

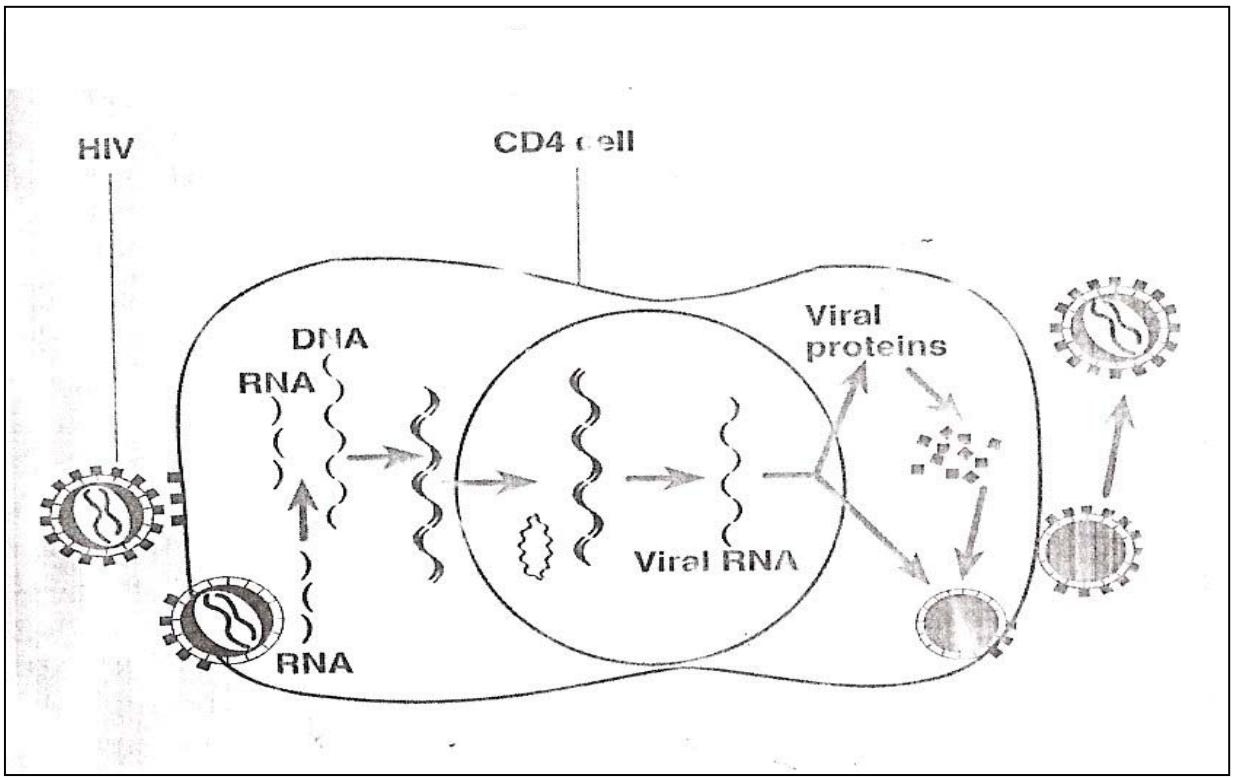
HIV/AIDS burden on hospitals in relation to HIV prevalence in health facilities

Study location	Burden as HIV prevalence in health facilities	Translation into a financial burden
Mama Yemo Hospital, Kinshasa, Democratic Republic of Congo (Hassig et al. 1990)	50% (1988, adult medical **inpatients**)	Costs and length of stay similar for HIV positive and HIV negative inpatients
Kenyatta National Hospital, Nairobi, Kenya (Gilks et al. 1998; Arthur et al. 2000)	18.7% (1988/89, adult medical **inpatients**)	
Kenyatta National Hospital, Nairobi, Kenya (Gilks et al. 1998; Arthur et al. 2000)	38.5% (1992, adult medical **inpatients**)	
Rubaga Hospital, Kampala, Uganda (Tembo et al. 1994)	55.6% (1992, adult medical **inpatients**)	Similar length of stay similar for HIV positive and HIV negative adult inpatients
Various hospitals (7), Zimbabwe (Hansen et al. 2000)	50% (1995, adult medial **inpatients**)	Costs for treating HIV positive **inpatients** almost twice that of HIV negative inpatients and much longer lengths of stay
Chris Hani Baragwanath Hospital, Soweto, South Africa (Meyers et al. 2000)	29.2% (1996, paediatric **inpatients**)	Longer inpatient stays for all HIV positive paediatric patients
Hlabisa Hospital, KwaZulu-Natal, South Africa (Yeung et al. 2000)	26% (1996/1997, paediatric **inpatients**)	
Kenyatta National Hospital, Nairobi, Kenya (Arthur et al. 2000; Guiness et al. 2002)	40% (1997 , adult medical **inpatients**)	Costs and length of stay similar for HIV positive and HIV negative inpatients
Tertiary level hospital, Durban, South Africa (Colvin et al. 2001)	54% (1998, adult medical **inpatients**)	
King Edward VIII hospital, Durban, South Africa (Pillay et al. 2001a)	62.5% (1998, paediatric **inpatients**)	Length of stay similar for HIV positive and HIV negative paediatric inpatients
St Mary's Hospital, Lacor, northern Uganda (Fabiani et al. 2003)	42% (1999, adult medical **inpatients**)	
Various hospitals and clinics across South Africa (Shisana et al. 2003)	46.2% (2002, medical and paediatric **inpatients**) 25.7% (2002,**outpatients**)	Longer inpatient stays for HIV positive patients, with presumed greater costs
Various Hospitals (4), Gauteng, South Africa (Schneider et al. 2005a)	38% -58.6% (2005, adult medical **inpatients**) 23.4%-31.5% (2005, paediatric **inpatients**) 34%-36% (2005, clinic **outpatients** presenting for curative care only)	Longer inpatient stays for all HIV positive patients
Tertiary hospital, Gauteng, South Africa (Thomas et al. 2006)	Costing study only (2005)	Longer **inpatient** stays and higher costs for HIV positive adult and paediatric patients

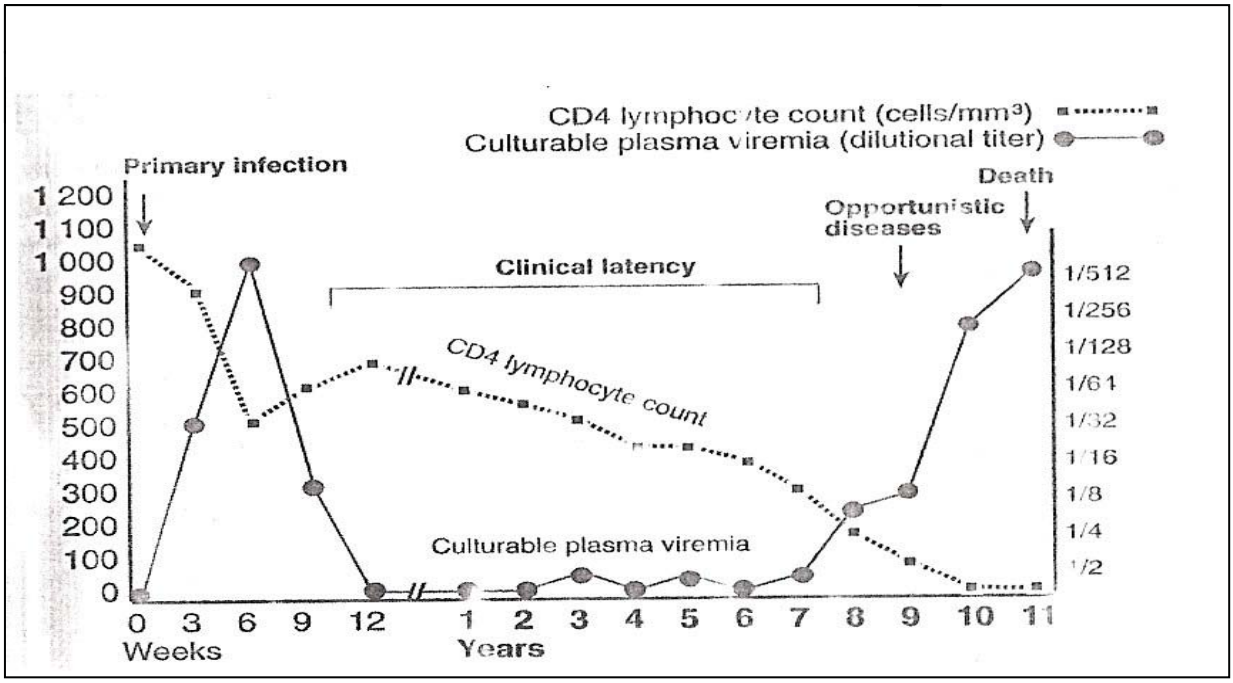
Source: (Veenstra 2007)

APPENDIX 9

The HI-Virus



Virus in action (Whiteside & Sunter, 2000/2001, p. 7)



Viral load and CD4 cell count over time (Whiteside & Sunter, 2000/2001, p. 9)

APPENDIX 10a

Stages of AIDS: ART initiation and WHO staging system of HIV

Table 1: Department of Health, South Africa: Criteria for ART initiation in adults and adolescents

• CD4 <200 cells/mm³ irrespective of stage
OR
• WHO Stage IV AIDS-defining illness, irrespective of CD4 count
AND
• Patient expresses willingness and readiness to take ART adherently

Table 2: WHO staging system for HIV and AIDS in adults

Stage I
1. Asymptomatic
2. Persistent generalised lymphadenopathy (PGL)
3. Acute retroviral infection (sero-conversion illness) and/or performance Scale 1: asymptomatic, normal activity
Stage II
4. Unintentional weight loss <10% of body weight
5. Minor mucocutaneous (e.g. seborrhoea, prurigo, fungal nail infections, oral ulcers, angular cheilitis)
6. Herpes zoster within the last five years
7. Recurrent upper respiratory tract infection (e.g. bacterial sinusitis) (URTI) and/or performance Scale 2: symptomatic, normal activity
Stage III
8. Unintentional weight loss >10% of body weight
9. Chronic diarrhoea >one month
10. Prolonged fever >one month
11. Oral candidiasis
12. Oral hairy leukoplakia
13. Pulmonary TB within the last year (PTB)
14. Severe bacterial infections (pneumonia, pyomyositis)
15. Vulvovaginal candidiasis >one month/poor response to therapy and/or performance Scale 3: bedridden <50% of the day during the last month

(Rehle, Shisana, Glencross, & Colvin 2005, p. 2)

APPENDIX 10b

Stages of AIDS: WHO staging system, stage IV, Indication for antiretroviral therapy

Stage IV
→ 16. HIV wasting (8 + 9 or 10)
17. *Pneumocystis carinii* pneumonia (PCP)
18. CNS toxoplasmosis (Toxo)
19. Cryptosporidiosis plus diarrhoea >one month
20. Isosporiasis plus diarrhoea
21. Cryptococcosis – non-pulmonary
22. Cytomegalovirus infection other than liver, spleen or lymph node (CMV)
23. Herpes simplex infection; visceral or >one month mucocutaneous (HSV)
24. Progressive multifocal leucoencephalopathy (PML)
25. Disseminated mycosis (i.e. histoplasmosis, coccidiomycosis)
26. Candida oesophageal/tracheal/pulmonary
27. Atypical mycobacteriosis disseminated (MOTT)
28. Non-typhoidal salmonella septicaemia
29. Extra-pulmonary tuberculosis (ETB)
30. Lymphoma
31. Kaposi's sarcoma (KS)
32. HIV encephalopathy (ADC)
33. Invasive cervical carcinoma and/or performance Scale 4: bedridden >50% of the day during the last month

Table 3: US Department of Health and Human Services (DHHS): Indications for antiretroviral therapy in HIV-1 infected adults and adolescents

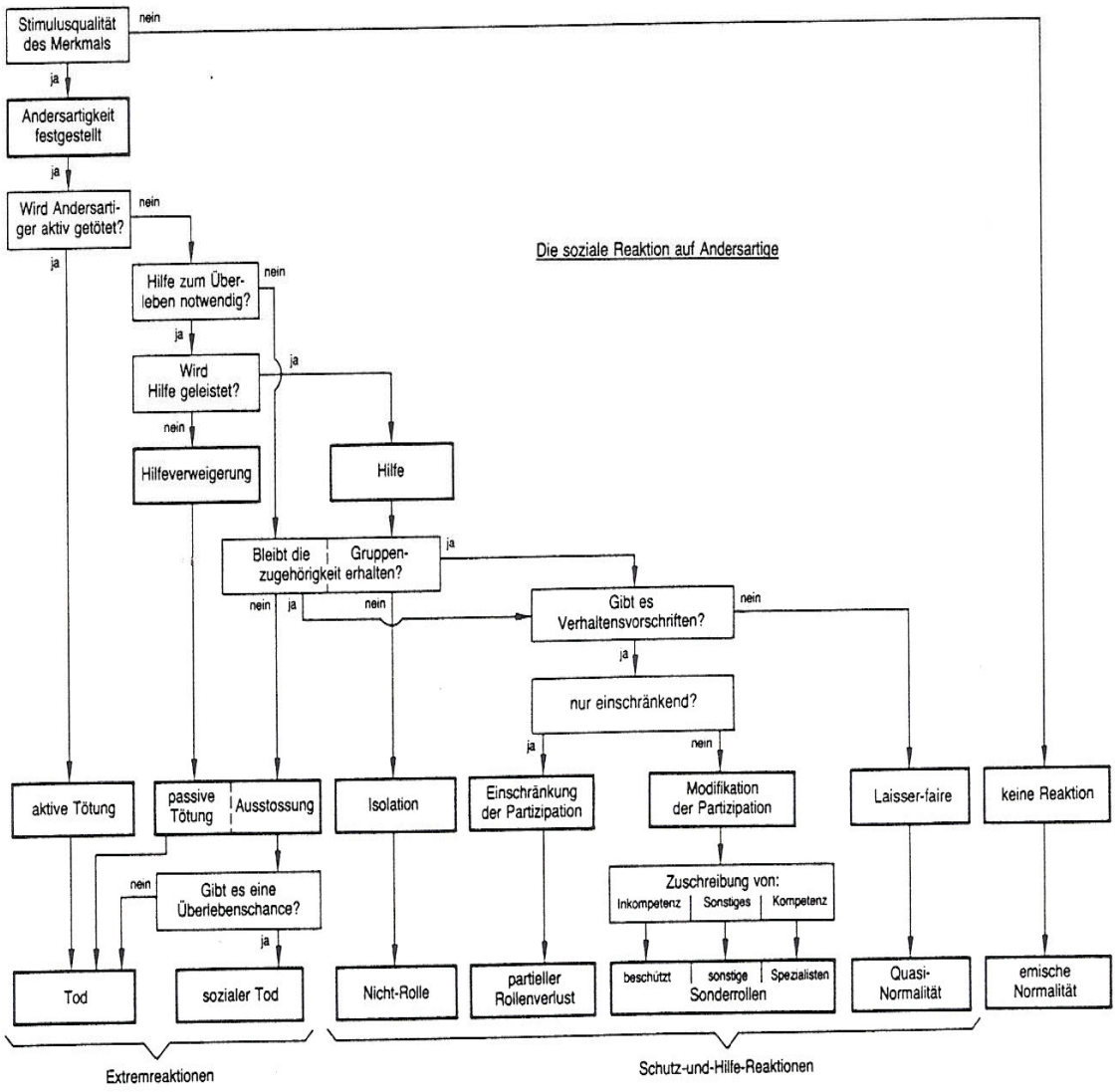
• Antiretroviral therapy is recommended for all patients with history of an AIDS-defining illness or severe symptoms of HIV infection regardless of CD4+ T cell count
• Antiretroviral therapy is also recommended for asymptomatic patients with <200 CD4+ T cells/mm³
• Asymptomatic patients with CD4+ T cell counts of 201–350 cells/mm³ should be offered treatment
• For asymptomatic patients with CD4+ T cell of >350 cells/mm³ and plasma HIV RNA >100,000 copies/ml most experienced clinicians defer therapy but some clinicians may consider initiating treatment
• Therapy should be deferred for patients with CD4 + T cell counts of >350 cells /mm³ and plasma HIV RNA <100,000 copies/ml

Source: Department of Health and Human Services, 2004

(Rehle, Shisana, Glencross, & Colvin 2005, p. 3)

APPENDIX 11

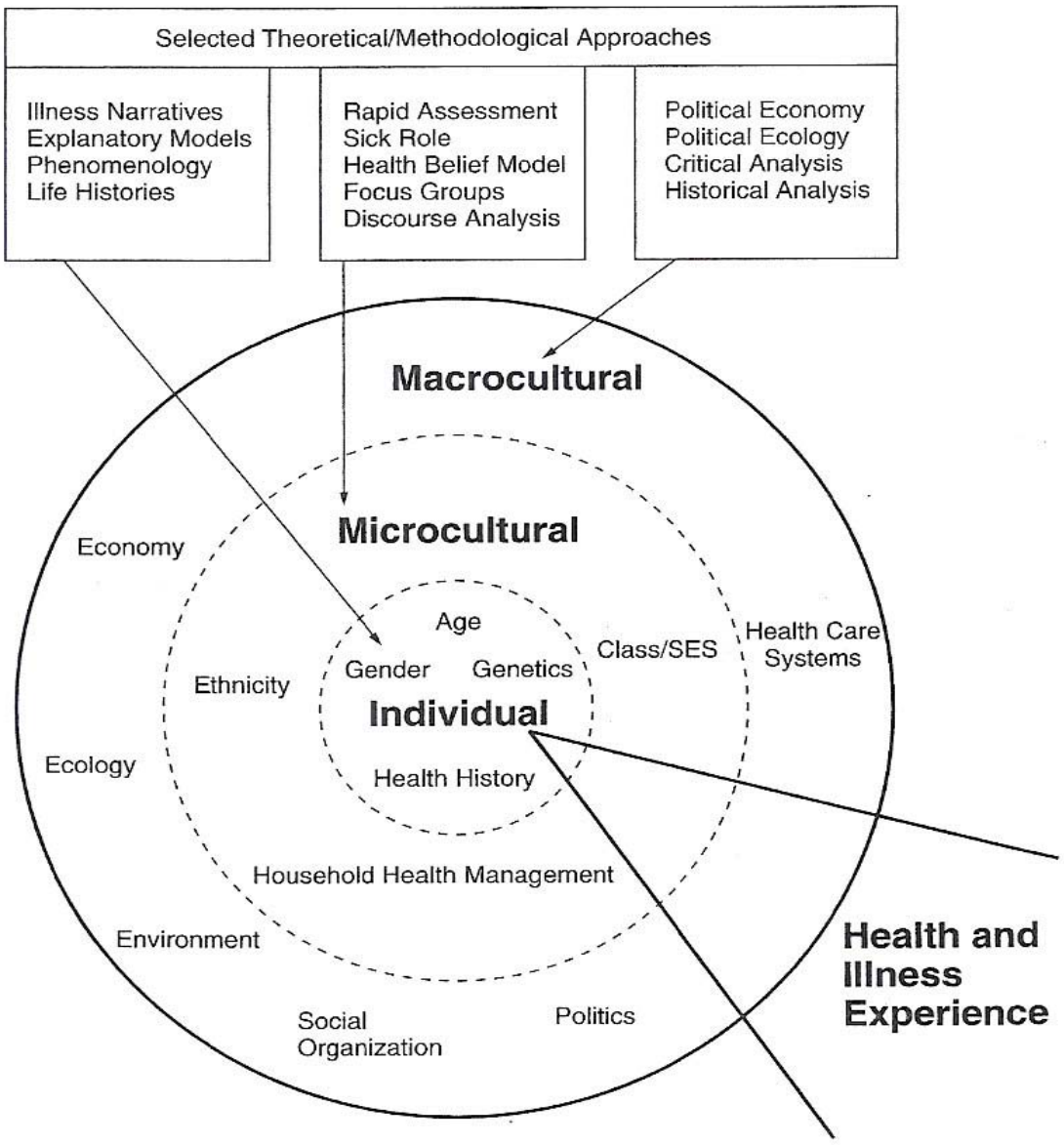
Neubert and Cloerkes model of reactions to abnormalities



Source: (Neubert & Cloerkes, 1994, p. 55)

APPENDIX 12

Analytic domains in the experience of health and illness



McElroy and Jewzeski 2000, p. 192

Appendix 13

Health seeking behaviour sorted in biomedical terms

	Western Medicine		Traditional Healer		Treat at Home	
	First resort	Second resort	First resort	Second resort	First resort	Second resort
Athsma	87.7	86.1	0.5	5.9	11.8	8.0
High Blood Pressure	88.8	89.6	1.9	4.0	9.3	6.4
Recurring Fever	41.6	72.8	1.3	3.7	57.1	23.5
Frequent Dizziness	74.7	76.3	6.2	14.2	19.1	9.4
Persistent Cough	40.0	69.3	1.3	4.5	58.7	26.1
Headaches	60.0	69.1	10.4	20.3	29.6	10.7
Impotency	86.3	83.3	8.5	13.5	5.2	3.2
Infertility	63.8	55.6	31.2	40.8	5.0	3.6
Intestinal Problems	43.0	48.1	39.8	46.5	17.1	5.3
Stomach problems	68.5	73.5	8.0	17.1	23.5	9.4
Liver problems	90.3	93.0	2.7	3.2	7.0	3.8
Mental illness	52.9	46.5	42.0	51.3	5.1	2.1
Menstruation problems	81.6	86.4	1.1	4.5	17.3	9.1
STDs	91.5	90.1	3.5	5.1	5.1	4.8
Tuberculosis	94.4	93.9	0.5	1.9	5.1	4.3
Malaria	91.2	96.0	0.5	1.6	8.3	2.4
Childbirth	74.3	88.3	8.7	4.1	17.1	7.6
Diarrhoea	33.8	82.7	1.9	4.3	64.4	13.0
Bleeding nose/mouth	53.2	61.6	19.7	31.5	27.1	6.9
Sore eyes/ears	78.9	86.3	1.6	8.6	19.5	5.1
Epilepsy	54.5	48.0	39.8	47.7	5.6	4.3
AIDS	93.4	90.1	2.1	5.4	4.5	4.5

Health-Seeking Behaviour by type of illness in Nattrass (2005, p. 168)

	1		2		3	
Dependent Variable: Sangoma client	dy/dx	x	dy/dx	x	dy/dx	x
Age	-0.001	38.6	0.002	38.6	0.002	38.6
Female	0.0127	0.608	0.064	1	0.055	1
Education	-0.001	9.02	-0.004	9.02	-0.003	9.02
Disability grant recipient	0.100	0.088	0.284	1	0.284	0
Total personal income (log)	-0.008	4.858	-0.034	4.858	-0.035	4.858
Income of other household members	-0.007	5.000	-0.344	5.000	-0.031	5.000
Traditional healing paradigm – AIDS	0.023	0.342	0.105	1	0.087	1
Poor health in 2000	0.036	0.218	0.145	1	0.116	1
Trust in people	-0.014	3.624	-0.069	0	-0.063	0
Marginalised in 2000	0.047	0.769	0.314	1	0.216	1
Predicted probability	0.0370076		0.59360687		0.31010576	

Probabilities of being a Sangoma Client in Nattrass (2005, p. 179))

APPENDIX 14

Newspaper article: Witch burning

13 charged for 'witch burning'

LATOYA NEWMAN

THIRTEEN people, some of them teenagers, are expected in court today after being arrested this week for the brutal beating and burning of a north Durban couple they believed had used witchcraft to kill children in their community.

The police said villagers of Ntshwani, in Stanger, had killed a 48-year-old man and his girlfriend last weekend. They were beaten with sjamboks, batons and sticks before being forced into their home which was then set on fire.

The community believed the couple were instrumental in the deaths of six children in the area by their alleged use of witchcraft. The children died over a period of two years. The police believe the children died of natural causes.

KwaDukuza police spokesman Vishnu Subramoney said: "On Saturday morning community members of Ntshwani in Stanger accused a man, 48, and his girlfriend, 35, of performing witchcraft and killing six children over a period of two years. We know the children died of natural causes. A group of about 15 people got together and assaulted them with sjamboks, batons and sticks. They then put them into a house and set the house on fire.

"We arrested 13 people, aged from 13 to about 60. One of them is the induna (chief) of the community. One suspect was also found in possession of an unlicensed firearm and rounds (of ammunition)."

The 35-year-old daughter of the man also lived in the community. She has been forced to flee for her safety.

All the accused face charges of murder and arson and are expected to appear in court today.

Source: The Mercury 29.07.2005

APPENDIX 15

Newspaper article: severely disabled girl raped

Severely disabled girl raped

BONNY VERWEY

A SEVERELY disabled 11-year-old girl was raped in a rural area near Hluhluwe at the weekend, allegedly by a relative, police reported yesterday.

The girl is wheelchair-bound and dumb.

Police spokesman Jay Naicker said the girl was asleep in her room on the family homestead in the Ekuphindiseni area on Saturday night when her aunt heard a sound in the room.

The aunt went to check and found her 22-year-old relative lying on her bed.

"The suspect fled when the aunt proceeded to call other family members. He was found later that night and was questioned by family members as to his presence in the victim's room. He denied any wrongdoing and was released by family members," he said.

However, the following day, while bathing the girl, her aunt noticed that she had bruising in the genital area. Suspecting that she had been raped, the aunt took her to the police station and then the district surgeon where it was confirmed that she had been raped.

Naicker said the case was reported to the police and the man was arrested. He is expected to appear in the Hluhluwe Magistrate's Court today.

Vulnerable

According to Childline director Joan van Niekerk incidents of abuse of disabled children occur "far more often than the public thinks".

Van Niekerk said disabled children, especially those with mental disorders and those who were dumb, were more vulnerable and "far easier to victimise".

Van Niekerk said cases involving children who were unable to communicate often also posed a challenge to the police and courts because there were usually problems taking their statements or leading their evidence.

She said rapists thought there was less likelihood of justice being served if the child was disabled. However, she added that prosecutors were making a "huge effort" to take such children through the legal processes.

People Opposing Woman Abuse spokeswoman Carrie Shelver said it was "absolutely frightening" that a crime of this nature could be perpetrated.

Shelver said that the laws in place to protect women and children from violence, especially sexual violence, were "not worth the paper they were written on" if societal attitudes were not changed.

Source: The Mercury 29.07.2005

APPENDIX 16

Results of the Ranking Exercise

Interview number	Access	Attitude	Believes	Employ.	Honesty	Independ.	Poverty	Protection	Relations.	Sexuality	Sex	urban/rural
1											female	urban
2											female	urban
3											female	urban
4											male	urban
5											female	urban
6	3	4	6	1	9	10	2	5	7	8	male	urban
7	7	1	3	5	9	4	6	8	2	10	male	urban
8	6	1	4	5	7	9	8	3	10	2	female	urban
9	4	1	2	10	7	8	9	6	3	5	male	rural
10	1	7	8	10	6	2	9	4	5	3	female	urban
11	3	2	1	4	7	5	10	5	9	8	female	urban
12	2	3	5	6	8	10	9	4	7	1	female	urban
13	3	7	8	4	10	9	2	6	1	5	female	rural
14	3	4	10	6	9	5	8	7	1	2	female	rural
15	8	3	7	6	9	4	5	1	10	2	female	urban
16	1	3	2	4	7	6	5	8	9	10	male	urban
17	9	2	3	1	7	8	4	6	10	5	male	rural
18	2	5	9	4	8	6	3	10	1	7	male	rural
19	5	7	8	3	10	9	2	6	1	4	female	rural
20	3	8	4	2	10	9	1	5	7	6	male	urban
21	4	8	3	9	6	5	10	7	2	1	female	urban
22	2	4	6	1	7	8	5	3	10	9	male	urban
23	2	8	10	4	6	7	1	5	7	3	female	urban
24	4	2	5	3	10	8	7	9	6	1	female	urban
25	5	4	10	1	6	3	2	7	8	9	male	urban
total	77	84	114	89	158	135	108	115	116	101		
male	36	32	45	29	70	62	37	58	57	69		
female	41	52	69	60	88	73	71	57	59	32		
disabled	47	34	52	49	84	77	65	73	65	59		
professinals	27	46	52	34	65	53	35	35	50	40		
biggest problem		second biggest problem				third biggest problem						